#### A DIFFERENT JOURNEY

## INTERNET MINISTRY TO PERSONS WITH DISABILITIES

#### A NEW APPROACH TO EVANGELIZATION

by

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## In Memory of

Nathan Patrick Gabriel McNulty (April 19, 1996 to September 14, 2000)

He was our "Gift from God" who taught us to believe in miracles and God's gracious love.

Now he is our angel who continues to inspire us
to reach out to others and share the
gifts we have received

With love

Let mutual love continue.

Do not neglect to show hospitality to strangers,

For by doing that

Some have entertained angels

Without knowing it.

Hebrews 13: 1-2

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#### A DIFFERENT JOURNEY

## INTERNET MINISTRY TO PERSONS WITH DISABILITIES

#### **ABSTRACT**

by

#### DENNIS C. MCNULTY

This D.Min. project investigates use of an internet website as pastoral ministry assisting the integration of persons with disabilities into the church.

The author presents a theological/theoretical basis for integration. Topics include social justice, causes for the marginalization of persons with disabilities, ecclesiology, personhood, sacramental theology, and Canon Law. He suggests pastoral approaches and use of the internet as a ministerial tool.

The author considers important items such as, methodologies, financial considerations, and forming a survey team to help create and evaluate the website. He describes details in creating a website.

Evaluation utilizes surveys over five months and offers participant demographics and detailed results. Surveys outline the success of the website and its value as a pastoral tool. The goal: can a website assist the integration of one person into the church?

Finally, the author offers reflections, conclusions, and suggestions for furthering this ministry on the national and local diocesan level.

## CONTENTS

ACKNOWLEDGEMENTS vi
ABSTRACT viii
LIST OF TABLES
Chapter
1. OVERVIEW
2. THEOLOGICAL/THEORETICAL FOUNDATIONS 10
Introduction
Our Mission
Section 1: Our Call to Integrate Persons with Disabilities
Social Justice
Historic Causes
Social/Economic Position of Persons with Disabilities in American Society
Words as Acts of Oppression
Ecclesiology and the Place of Persons with Disabilitics
The Church as Servant
The Church as the Community of Disciples
Personhood
Section 2: Sacramental Integration as the Starting Point for full Participation in the Church
Current pastoral obstacles in the reception of Eucharist
An understanding of the Real Presence in Eucharist
Canonical Rights to Eucharist

# Section 3: Suggestions for Pastoral Practices/ Pastoral Statements/Pastoral resources

## The Call to Integration

arm .	
Evangel	lization
T + C411 T C	ILLUIT

3.	PROJECT METHODOLOGY
	Revisiting the Mission
	Determining the Target Group
	Determining the Originality of the Project
	Determining the Necd
	Determining the Cost
	Funding the Project
	Creating a Project Chart
	Forming a Focus Group
	Choosing a Website Domain Name
	Choosing a Website Host
	Constructing the Website
	Selecting the Survey Team
	Launching the Website
	Enhancing the Website
	Promoting the Website
4.	SUMMARY AND ANALYSIS OF SURVEY DATA 102
	Part 1: Quantitative Data: Demographic Information
	Part 2: Qualitative Data
	Overall Results of the Pre-Survey

Subgroup Response	s to the Fre-Survey
Overall Selection of	Topics for the Website
Subgroup Selection	of Topics for the Website
Overall Subjective S for the Webs	_
Subgroup Subjective for the Webs	e Selection of Topics site
Part 3: Post-Survey Evaluat	ion of the Website
Statistical Results	
Evaluation of Goal	One
Evaluation of Goal	Гwо
Evaluation of Goal	Гһгее
Part 4: Conclusion	
5. REFLECTIONS AND CONCL	USIONS 136
Can a Website Be a Valid A	Approach to Pastoral Ministry?
What Was Learned?	
Next Steps	
Appendix	
A. TEN PRINCIPLES OF SOCIA EXAMPLE OF THEIR US PASTORAL STAT	
B. SELECTED STATISTICS FRO	OM THE IVE 154
C. FINDINGS FROM THE 2000	CENSUS SURVEY 156
D. PROJECT TIMELINE	

D.I: Proposed Project Timeline	
D.2: Project Timeline Showing Completion Points	
E. NAMES AND TITLES OF THE MEMBERS OF THE FOCUS GROUP	161
F. BEATITUDES FOR PEOPLE WITH SPECIAL NEEDS	163
G. FOCUS GROUP AGENDAS	165
G.I: February 2, 2006	
G.2: Minutes for the February 2, 2006 Meeting	
G.3: September 27, 2006	
H. PARTICIPANT COVER LETTERS AND SURVEYS	170
H.1: Participant Cover Letter and Participant Questionnaire	
H.2: Cover Letter and Pre-Survey	
H.3: Cover Letter and Post-Survey	
I. PARTICIPANT COMMENTS AND SUGGESTIONS	180
I.1: Website Comments for June 2006	
<ul><li>I.1: Website Comments for July 2006</li><li>I.2: Website Comments for July 2006</li></ul>	
I.2: Website Comments for July 2006	186
<ul> <li>1.2: Website Comments for July 2006</li> <li>1.3: Website Comments for August 2006</li> <li>J. ARTICLE FROM THE CATHOLIC UNIVERSE BULLETIN ON CATHOLICDISABILITYTEACHINGS.COM</li> </ul>	

M.	THE PARTICIPANT QUESTIONNAIRE WITH THE DEMOGRAPHICS OF THE POST-SURVEY	204
	M.I: Comparison of Respondents by Subgroup	
	M.2: Comparison of Overall Demographics	
	M.3: Graphs Comparing Overall Demographics	
N.	RESPONSES BY SUBGROUPS TO THE EIGHT STATEMENTS OF THE POST SURVEY	208
Ο.	SUBGROUP'S CHOICES OF FAVORITE WEBSITE PAGES	213
Р. :	SURVEY SENT TO PARTICIPANTS WHO DID NOT RESPOND TO THE POST-SURVEY AND THE RESULTS	215
	P.1: Email Survey Sent to Participants Who Did Not Respond to the Post-Survey	
	P.2: Results of Survey Sent to Participants Who Did Not Respond to the Post-Survey	
Q.	DIOCESAN MODELS OF MINISTRY TO PERSONS WITH DISABILITIES	218
ANNOTA	TED BIBLIOGRAPHY	224

## LIST OF TABLES

Tal	ble	Page
1.	Respondents by Gender	103
2.	Respondents by Raee	103
3.	Respondents by Age	105
4.	Respondents Description of Self	107
5.	Respondents' Familiarity with Types of Disabilities	108
6.	Total Responses to the Five Statements of the Pre-Survey	111
7.	Overall Selection of Topics for the Website	115
8.	Subgroups Prioritization of Website Topies	117
9.	Total Responses to the Eight Statements of the Post-Survey	122
10.	. Most Helpful/Informative Areas of the Website	131

#### CHAPTER 1

#### **OVERVIEW**

A doctor of ministry program "...is designed to foster the development of the ministers' understanding of the contexts of their ministries within the Christian community, and to help them situate their ministries within the total life of the Church."

A doctor of ministry project seeks to add to the body of knowledge by presenting new theological insights and approaches or by developing concrete pastoral practices that enhances a specific area of ministry. This project intended to accomplish both objectives. This chapter presents an overview of a project that is meant to add to the field of ministry to persons with disabilities. The project attempted to accomplish this task on two levels. First, this paper presents a unique theological and theoretical foundation for the integration of persons with disabilities into the total life of the church. Second, a pastoral project investigated the value of using an internet website to promote the church's teachings on persons with disabilities and provide ministerial advice and suggestions. The goal of the paper and the website are the same. The two parts of this project attempt to further the integration of persons with disabilities into the church.

This paper is divided into five chapters. Following the overview of Chapter 1, Chapter 2 presents the theological/theoretical foundation for integration. Chapter 3 provides a summary of the methodology employed to create the website. Chapter 4 examines the

<sup>&</sup>lt;sup>1</sup> *Doctor of Ministry Program,* Dr. Edward Kaczuk, Webmaster, St. Mary Seminary and Graduate School of Theology, [website on-line] (2007, accessed January 22, 2007); Available from http://www.slmarysem.edu/DMin.htm; Internet.

2

survey team that assisted in the creation of the website and, ultimately, evaluated it. Lastly, Chapter 5 presents personal reflections, conclusions, and future direction for the ministry for persons with disabilities.

As mentioned above, Chapter 2 presents the theological and theoretical basis for the project. This chapter forms the heart of the rationale for actively encouraging persons with disabilities to participate in all aspects of Church life. The purpose of this chapter lays a theological/theoretical foundation for the right of persons with disabilities, as all Catholics, to full participation in the church, sacramentally, liturgically and socially, according to their interest and abilities. The author's presentation is based on the church's call to integrate persons with disabilities into its community as well as the person with disabilities' call to be part of the faith community. These two perspectives form the rationale for integration.

Chapter 2 presents a unique approach. As evidenced in much existing literature, it deals with *how* to include persons with disabilities. More importantly, Chapter 2 considers *why* we are called to integrate persons with disabilities into the fabric of the church. This second consideration lays the foundation for all parts of the overall project.

To accomplish these goals. Chapter 2 is divided into three sections that are interconnected. Section one considers the church's call to integrate persons with disabilities, based on the church's call to social justice. Attendant to the description of this call, the author considers the marginalization of persons with disabilities from an historical perspective. He then presents these historical events and attitudes as influencing the present social position of persons with disabilities in society. This social position is demonstrated by recent statistics and surveys. The author reflects on the subordinate place of persons with disabilities by considering a few of the terms used to

refer to these individuals by society. Chapter 2 demonstrates how labels have been a means of oppression. Finally, the author considers the church's call to integration in light of ecclesiology. One model of the church, as originally presented by Avery Dulles, is singled out and presented as a paradigm that prompts the church to actively integrate persons with disabilities.

Chapter 2 then considers the call of persons with disabilities to be part of the life of the church. Continuing with Dulles's models, the author presents a second model of the church which focuses on the people as called to discipleship. This call to equal discipleship is based in the notion of complete personhood as created in the image of God. The author employs Catherine LaCugna's Trinitarian Theology to present an approach to personhood that encompasses all individuals. From this perspective, a conclusion is made that the church's mission to integration is simply the recognition of the call God is extending to all persons, including persons with disabilities, to be part of the Kingdom.

The second section of the chapter then considers pastoral practices focusing on the area of sacramental reception. This section emphasizes sacramental inclusion as the starting point for complete integration into the church. The author accents sacramental pastoral practices because it is at points of reception of the sacraments, particularly the Sacrament of Eucharist, when persons with disabilities are often refused participation. Current obstacles to the sacraments are considered. The author examines theologies of Thomas Aquinas, Edward Schillebeeckx, David Fagerberg, Kevin Irwin, among others, who present approaches to Eucharist that enhance the traditional perspectives.

As with pastoral practices, Catholic Canon Law is often the basis for refusal in sacramental participation. For this reason, the author then considers Canon Law in Chapter 2. Detailed are the interpretations of Canon Law of Canonists such as Peter Vere and John Huels that clearly include persons with disabilities.

The chapter concludes with a third section which presents a few general pastoral suggestions to enhance the integration of persons with disabilities into the church. Looking toward the actual website project itself, Chapter 2 argues that the church's call to integrate prompts us to utilize various means to promulgate beliefs, to evangelize, and to call forth persons with disabilities. The Church already utilizes different methods to reach out to persons with disabilities, to welcome them, and to assure them of their place in the Church. Books, articles, videos, presentations and the pastoral statements themselves are employed to instruct pastoral ministers and to be a means of outreach to people with disabilities and their families. Chapter 2 concludes by suggesting the possible use of internet technology as one new tool to accomplish this mission. Building a website is a means to an end. One objective was to determine the value of the site. If the web site could assist one person to access church or to be further integrated into it, the project would be a success.

The foeus of the pastoral project was the creation of an internet website to test the theory that its use would be a valuable pastoral tool. The site presented visitors with information on the ehurch's beliefs about persons with disabilities. It was from this foundation that the website presented practical suggestions on *how* to integrate persons with disabilities into church life.

Chapter 3 presents various methodologies employed in developing, building and sustaining this new website. An important goal of the project was to determine if the use of an internet website is a valuable method of promoting the teachings of the church while providing practical pastoral information. The answer to this question determined its value to the ministry to persons with disabilities.

The result was not just *any* website. As an investigation into the ministerial use of a website, the procedures were more intricate than with the creation of a typical website. Chapter 3 discusses many of the methodologies that went into the project. Such considerations include:

- The mission and goals of the project. Why is it important to revisit the mission and goals throughout the project?
- Determining the target group. Who does the website want to attract?
- Determining the originality of the project. Has it been done already?
- Determining the need. Does one exist?
- Determining the cost. Can the creator afford the cost? How does one reduce the cost?
- Creating a project chart to complete the task on time. How can the chart assist?
- Forming a focus group to act as primary advisors.
- Choosing a website domain name. Why is the name important?
- Choosing a website host. What should be considered in selecting a place for the website?
- Constructing the website. What general steps were taken to complete the site?
- Selecting the survey team. The survey team will determine the success or failure of the project. How does one go about choosing the mcmbers?
- Launching the website. What steps are involved in putting the website on the internet?
- Enhancements to the website. How was the website enhanced with the input of the survey team?
- Promoting the website. How to attract the intended target group to visit the website?

The methodology presented in this chapter is not sequential for many items overlapped or were performed or considered concurrently. The points presented are not all-inclusive. Chapter 3 highlights only the key elements employed in the construction of

this particular website. The methodology involved more than just the website and its construction and content. The project also involved the study and evaluation of a survey team that assisted in the creation of the site. Once the website existed, this same group evaluated the site on a monthly basis. The culmination occurred with the completion of a post-survey evaluation. It was from the various evaluations and comments that the website was considered a success or a failure.

While Chapter 3 presents an overview of the methodology that was employed in building the website, Chapter 4 analyzes statistical information that was gathered during the project. This information indicates the determination of the project's success or failure. Chapter 4 considers qualitative (opinions, advice, or suggestions) as well as quantitative data (personal background information). The author divides Chapter 4 into four sections. First, quantitative data is presented based on the initial Participant Questionnaire, which prospective members of the survey team completed to be selected for the project. Chapter 4 then presents qualitative data first from the Pre-Survey (completed after the final members of the survey team were selected), and then evaluative data is drawn from the Post-Survey (completed at the conclusion of the project). The fourth section of the chapter judges the success or failure of the project as indicated from the data.

The author gathered all data from the group of people who volunteered to participate in this website project. The quantitative data consisted of information gathered at the beginning of the project. It was composed of demographic information such as gender, race, age, and how the participants described themselves (priest, religious, parent, person with a disability, etc.). The author analyzed the information to

determine who would be part of the survey team and whether it was representative of society.

The largest section of Chapter 4 is dedicated to the qualitative data. This information was gathered from a pre and post survey. This information indicated the participants' individual interest areas and areas that are of concern to specific groups such as priests, parents, or persons with disabilities.

The research for this project was evaluative. The author studied the level of knowledge of the participants and their perceived areas of interest. In order to apply the findings to an instructional web site, the Pre-Survey focused on two goals. The first was to determine the participants' level of understanding of church teachings and pastoral practices in the area of ministry to persons with disabilities. The second goal of the Pre-Survey was to determine the type of information that such a website should provide. This second goal helped construct the initial website. Chapter 4 analyzes this survey for indications of trends.

At the conclusion of the project, a Post-Survey evaluated the website. Would the website achieve its goals? How usefulness was the website in disseminating theological Church teachings and pastoral suggestions? How helpful was the website to visitors in the context of their lives? The results of the Post-Survey presented in Chapter 4 determine whether the website was a success or not. On a fundamental level, was the website-based medium considered a value to the participant? Is it a useful method of presenting information on the integration of persons with disabilities into the church? The final section of Chapter 4 presents a conclusion to these questions and objectively determines the success or failure of the project.

The concluding chapter of this work presents personal reflections and conclusions. Chapter 5 has three parts. The first section considers and reflects on the success or failure of the use of a website as a ministerial tool. This section continues from the conclusions of Chapter 4 on the success or failure of the project. The author considers additional feedback received from visitors to the website who were not part of the survey team.

Next Chapter 5 considers what was learned from the project. In the process of the project, what was learned? What was surprising? Was some new information acquired? Was something new uncovered?

Lastly, the author considers what next steps are called for in the further integration of persons with disabilities into the church. What does the project call for as far as the website itself, the Catholic Diocese of Cleveland, Ohio<sup>2</sup> and universal church to further assist persons with disabilities to be further integrated into the church? Are there areas that need further research? Does this project raise questions about pastoral practices? If someone were to continue this study, what areas of need might be considered next?

To summarize, the fundamental question addressed in this study is whether the use of internet technology can assist persons with disabilities, their families, and those who provide pastoral ministry to them to access information on church teachings and pastoral practices. This project attempted to provide information in a new way that is assistive and interactive. This author attempted to develop a new ministerial tool to

<sup>&</sup>lt;sup>2</sup> Throughout these pages the Catholic Diocese of Cleveland. Ohio will received particular attention. The reason for this is that the author has served this Diocese as Director of Catholic Charities Disability Services since 1986. As a result, he has a particular interest in ministries to persons with disabilities in the eight counties of this Diocese. Catholic Charities Health and Human Services of the Cleveland Diocese will be referred to for the same reason.

enhance the integration of persons with disabilities into the church. This study imagines a new way for people to know that they are welcome as full participants in the church community.

#### CHAPTER 2

#### THEOLOGICAL/THEORETICAL FOUNDATIONS

#### Introduction

The purpose of this chapter is to lay a theological/theoretical foundation for the right of persons with disabilities, as all Catholics, to full participation in the church, sacramentally, liturgically and socially, according to their interest and abilities. The author bases his approach on two perspectives. First, the church's call to integrate persons with disabilities is explored. This chapter then considers the person with a disability's call to participate in the community of faith. These two perspectives are based on our call as church and the God-like personhood and nature of persons with disabilities. In this chapter, the author presents the theological/theoretical foundations for all aspects of the overall project, the creation of an internet website. The site presented visitors with information on the church's beliefs about persons with disabilities. It is from this foundation that the *how* to integrate persons with disabilities was considered by suggesting practical pastoral advice. This chapter has the same goal as the website. The goal of both is to further the integration of persons with disabilities into the church community.

#### Our Mission

Every person is called to be part of the Kingdom that God is creating. The God who calls all to be one calls all, *as they are*, with their limitations and their talents.

Persons with disabilities are also being called by God to participate in the life of the church and the Kingdom. However, they have yet to realize their equality in ministry and their giftedness in the church. The world tempts us to view people as inferior because of their differences. Christ calls us to a higher standard of vision. Pope Benedict XVI reminds us of this different standard in his lnauguration homily.

We are living in alienation, in the salt waters of suffering and death; in a sea of darkness without light. The net of the Gospel pulls us out of the waters of death and brings us into the splendour (sic) of God's light, into true life. It is really true: as we follow Christ in this mission to be fishers of men, we must bring men and women out of the sea that is salted with so many forms of alienation and onto the land of life, into the light of God. It is really so: the purpose of our lives is to reveal God to men. And only where God is seen does life truly begin. Only when we meet the living God in Christ do we know what life is. We are not some casual and meaningless product of evolution. Each of us is the result of a thought of God. Each of us is willed, each of us is loved, each of us is neeessary. There is nothing more beautiful than to be surprised by the Gospel, by the encounter with Christ. There is nothing more beautiful than to know Him and to speak to others of our friendship with Him. The task of the shepherd, the task of the fisher of men, can often seem wearisome. But it is beautiful and wonderful, because it is truly a service to joy, to God's joy which longs to break into the world.3

Pope Benedict began his pontificate with a poetic summary of the world we live in versus the beliefs that unite us as Christians. These words could not be truer in regard to persons with disabilities. In many respects these persons are living in an alienated reality, separated from others by prejudiee and long-standing presumptions about their place in society. In the midst of this milieu there stands a hope, a belief that all people are created by God for a purpose. Pope Benedict stresses that, "Each of us is willed, each of us is loved, each of us is necessary."

<sup>&</sup>lt;sup>3</sup> Pope Benedict XVI, *Homily of his Holiness Benedict XVI*. Mass for the Inauguration of the Pontificate of Pope Benedict XVI. St. Peter's Square, 24 April 2005 [Homily on-line] (2005, accessed January 4, 2006); Available from <a href="http://www.vatican.va/holy\_father/benedict\_xvi/homilies/documents/hf\_ben-vi\_hom\_20050424\_inizio-pontificato\_en.html">http://www.vatican.va/holy\_father/benedict\_xvi/homilies/documents/hf\_ben-vi\_hom\_20050424\_inizio-pontificato\_en.html</a>; Internet.

Many writings on the complete inclusion of persons with disabilities into the life of the church simply assume the place of persons with disabilities in the church. They deal with the *how* of inclusion but not the *why*. Is integration simply an act of charity on our part, or is it our obligation as part of our call as Christians? Persons with disabilities possess the image of God that calls them to respond by desiring complete participation. The church is only, in the end, recognizing their *God-like* nature that is part of all people.

#### Section 1: Our Call to Integrate Persons with Disabilities

#### Social Justice

63. In regard to the Church, her cooperation will never be found lacking, be the time or the occasion what it may; and she will intervene with all the greater effect in proportion as her liberty of action is the more unfettered. Let this be carefully taken to heart by those whose office it is to safeguard the public welfare. Every minister of holy religion must bring to the struggle the full energy of his mind and all his power of endurance. Moved by your authority, venerable brethren, and quickened by your example, they should never cease to urge upon men of every class, upon the high-placed as well as the lowly, the Gospel doctrines of Christian life; by every means in their power they must strive to secure the good of the people; and above all must earnestly cherish in themselves, and try to arouse in others, charity, the mistress and the queen of virtues. For, the happy results we all long for must be chiefly brought about by the plenteous outpouring of charity; of that true Christian charity which is the fulfilling of the whole Gospel law, which is always ready to sacrifice itself for others' sake, and is man's surest antidote against worldly pride and immoderate love of self; that charity whose office is described and whose Godlike features are outlined by the Apostle St. Paul in these words: "Charity is patient, is kind, . . . seeketh not her own, . . . suffereth all things, . . . endureth all things."4

The release of *Rerum Novarum* (On Capital and Labor), written by Pope Leo XIII in 1891, ushered in the birth of the modern social justice teachings. Since then, the church has accented the obligation for Christians to practice justice not as a personal act or out of a

<sup>&</sup>lt;sup>4</sup> Pope Leo XIII, *Rerum Novarum* (On Capital and Labor), Encyclical of Pope Leo XIII, May 15, 1891, Article 41; [Encyclical on-line] (1891, accessed January 25, 2006); Available from http://www.papalencyclicals.net/Leo13/113rerum.htm; tnlemet.

sense of charity, but as an obligation that flows from what church is ecclesiologically.

Justice and care for the marginalized, expressed as "preferential option for the poor" are basic tenets of what it means to be a member of the church. These principles have particular ramifications for persons with disabilities. The author considers these principles here to accent their importance to the call of the church community to integrate persons with disabilities as marginalized persons. A word of explanation of the principles, then, is in order.

The Church's social teaching presents a methodology for building a just society and for living lives of holiness amidst the challenges of modern society. Modern Catholic social teaching has been articulated through a tradition of papal, council, and episcopal documents. Following are several of the key themes that are at the heart of our Catholic social tradition with a brief explanation of each.

#### Life and Dignity of the Human Person

The Catholic Church proclaims that human life is sacred and that the dignity of the human person is the foundation of a moral vision for society. This belief is the foundation of all the principles of our social teaching. We believe that every person is precious, that people are more important than things, and that the measure of every institution is whether it threatens or enhances the life and dignity of the human person.

### Call to Family, Community, and Participation

The person is not only sacred but also social. How we organize our society in economics and politics, in law and policy directly affects human dignity and the capacity of individuals to grow in community. Marriage and the family are the central social institutions that must be supported and strengthened, not undermined. We believe people have a right and a duty to participate in society, seeking together the common good and well-being of all, especially the poor and vulnerable.

#### Rights and Responsibilities

The Catholic tradition teaches that human dignity can be protected and a healthy community can be achieved only if human rights are protected and responsibilities are met. Therefore, every person has a fundamental right to life and a right to those things required for human decency. Corresponding to these

rights are duties and responsibilities—to one another, to our families, and to the larger society.

#### Option for the Poor and Vulnerable

A basic moral test is how our most vulnerable members are faring. In a society marred by deepening divisions between rich and poor, our tradition recalls the story of the Last Judgment (Mt 25:31-46) and instructs us to put the needs of the poor and vulnerable first.

### The Dignity of Work and the Rights of Workers

The economy must serve people, not the other way around. Work is more than a way to make a living; it is a form of continuing participation in God's creation. If the dignity of work is to be protected, then the basic rights of workers must be respected—the right to productive work, to decent and fair wages, to the organization and joining of unions, to private property, and to economic initiative.

#### Solidarity

We are one human family whatever our national, racial, ethnic, economic, and ideological differences. We are our brothers' and sisters' keepers, wherever they may be. Loving our neighbor has global dimensions in a shrinking world. At the core of the virtue of solidarity is the pursuit of justice and peace. The Gospel calls us to be peacemakers. Our love for all our sisters and brothers demands that we promote peace in a world surrounded by violence and conflict.

#### Care for God's Creation

We show our respect for the Creator by our stewardship of creation. Care for the earth is not just an Earth Day slogan; it is a requirement of our faith. We are called to protect people and the planet, living our faith in relationship with all of God's creation. This environmental challenge has fundamental moral and ethical dimensions that cannot be ignored.<sup>5</sup>

The social justice themes permeate not only the specifically social justice statements, but also many other statements issued by the Vatican or more local sources, such as the United States Conference of Catholic Bishops. No longer presented separately, by the 1960's, the principles of social justice could be found interwoven in statements dealing with the call of and the ecclesiological nature of the church to practice justice. For example, the Pastoral Statement of U.S. Catholic Bishops on People with Disabilities issued in 1978

<sup>&</sup>lt;sup>5</sup> United States Conference of Catholic Bishops, "Themes of Catholic Social Teaching." (Washington: USCCB Publishing, 1972; accessed November 6, 2006); Available from http://www.usccb.org/sdwp/projects/socialteaching/excerpt.htm; Internet.

presents several references to the principles of social justice. Two examples and their application to persons with disabilities follow:

#### Dignity of the Human Person

On the most basic level, the Church responds to persons with disabilities by defending their rights. Pope John XXIII's encyclical *Pacem in Terris* stresses the innate dignity of all men and women. "In an ordered and productive community, it is a fundamental principle that every human being is a 'person'. . . . [One] has rights and duties . . . flowing directly and spontaneously from [one's] very nature. These rights are therefore universal, inviolable and inalienable."

The other example could fit several of the social justice principles. Flowing from the dignity of the individual, these principles give a person the right to participate in society. The "Call to Family, Community, and Participation" could be the basis of this statement. Or, viewing this idea from a different perspective, all persons have a right to participate in decisions that affect their lives fitting the principle "Rights and Responsibilities."

Defense of the right to life, then, implies the defense of other rights which enable the individual with a disability to achieve the fullest measure of personal development of which he or she is capable. These include the right to equal opportunity in education, in employment, in housing, as well as the right to free access to public accommodations, facilities and services.<sup>7</sup>

Contemporary pastoral statements demonstrate how the social justice principles are integrated into the teachings of the church. <sup>8</sup> Considering this evidence, it would be difficult to argue that they are not intrinsic to the call that each person receives from God.

Understanding that the individual Christian is called to build a just society, it is logical to

<sup>&</sup>lt;sup>6</sup> United States Conference of Catholic Bishops, *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities* (Washington: National Catholic Office for Persons with Disabilities, 1978 updated 1989 and 1999, accessed September 4, 2006); Available from <a href="http://www.ncpd.org/pastoral-statement-1978.htm">http://www.ncpd.org/pastoral-statement-1978.htm</a>; Internet, Article 7.

<sup>&</sup>lt;sup>7</sup> Ibid., Article 10.

<sup>&</sup>lt;sup>8</sup> For an alternate presentation of the principles of social justice and an example of their use in contemporary pastoral statements, see Appendix A.

view the role of the church, in any age, as called to be a sign to the world of God's mercy and justice. This sign is one of action in which justice is lived out. It is demonstrated by integrating those marginalized by society, as well as the outcast, not just into the social/political life of society, but accepted and integrated into the liturgical and social life of the church, as well. The church advocates for justice by example.

Every age calls the church to new social justice needs; new groups become the marginalized individuals resulting from the current milieu of oppression. Currently, the American attitudes toward persons with disabilities places them alongside other groups such as women, Hispanics, African Americans, and homosexuals, all of whom are in different stages of a struggle for acceptance and equality in the church and in society. The church has recognized its role in including many of these groups. However, the church is only beginning to truly integrate persons with disabilities.

It is possible to document that persons with disabilities are part of the marginalized segment of our society. The author demonstrates this fact by using several sources. First, it is demonstrated by considering a few historical causes; second, by examining recent statistics of the place that persons with disabilities hold in our society; and third, by referring to the labels that persons with disabilities receive from society and how these labels can be forms of oppression. The conclusion is that persons with disabilities are indeed marginalized by our society and the church reach out to them and integrate them as a matter of justice.

#### **Historic Causes**

Though there are many causes of current attitudes toward persons with disabilities, three movements that will be briefly considered as one continuum will be: (1) the

institutionalization movement between 1850 to approximately 1960, (2) the eugenics movement from the latter 1800's to around 1930 and (3) the deinstitutionalization movement and resulting social inclusion movement, beginning approximately in the 1960's, that is currently dominating American society. These movements are not separate, but are part of the same story that has helped shape current attitudes toward persons with disabilities. Although all disability groups share, in different degrees, the current attitude, here persons with cognitive disabilities and developmental disabilities will be highlighted, since their history is fairly well documented and the attitudes shown toward them often flows over to other groups. 9

One need only pick up the history of the American Association on Mental Retardation, the oldest American organization concerned with persons with cognitive disabilities, to discover the American attitude toward persons with disabilities. <sup>10</sup> This organization represented the attitudes of the leaders in the field and reflected the general American approaches to caring for persons with cognitive disabilities. The reader should note that the terms used in this section reflect their periods of history and were the accepted terms at that time for persons with disabilities. With this caveat, the terms themselves demonstrate an American attitude.

<sup>&</sup>lt;sup>9</sup> A Cognitive Disability is currently accepted in place of the traditional term, "Mental Retardation." By personal preference the author chooses to use "cognitive disability" throughout this paper. Another currently accepted term is Intellectual Disability. Generally, the presence of a cognitive disability indicates a lower (but not absent) intellectual functioning for the person. A Developmental Disability is a broader category and refers to various conditions that adversely affect some cognitive and/or physical functions of an individual–such as deafness, blindness, tourette syndrome or autism.

<sup>&</sup>lt;sup>10</sup> William Sloan and Harvey A. Stevens, *A Century of Concern: A History of the American Association on Mental Deficiency, 1876-1976* (Washington: The American Association on Mental Deficiency, Inc., 1979).

In 1876 a handful of men gathered for the founding of what became the American Association on Mental Retardation. Their purpose was to exchange ideas "relating to the care, training, and management of the idiot and the feebleminded." At the outset, consideration was given to training, but the establishment of institutions was equally important, if not more so. Institutionalization and the creation of facilities separated from the general population became the goal. Between 1876 till 1885 the "seeds for the concept of relatedness of criminality and imbecility were planted...extensive consideration was given to such things as etiology and classification, in addition to the nature, size, organization and educational programs of institutions and the care provided." 12

Between 1896 and 1905 the Association turned more and more toward a solution to the problem of those who were different. In 1894, The President of the Association, A. E. Osborne, reflected pubic attitudes toward persons with disabilities in a presidential address.

Perhaps some of you do not believe that the world is undergoing a revolution in thought regarding the status of the feebleminded and the true ethics of our institutional care for them. Then you are deceived. The people are realizing that our institutions are not doing all nor can they do all that needs to be done for defective, dependent and delinquent persons.<sup>13</sup>

Osborne continued by stating that, after fifty years of institutionalized care, there had been no measurable decrease in "mental enfeeblement among the masses nor have we been able to present any suitable working plans whereby our influence in this matter might become more extendable." <sup>14</sup>

<sup>12</sup> Ibid., 8.

<sup>11</sup> Ibid., 8.

<sup>&</sup>lt;sup>13</sup> Sloan and Stevens; President's Address of A. E. Osborne. Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, 1894, 389.

<sup>&</sup>lt;sup>14</sup> Ibid., 391.

He cited data that indicated that almost two percent of the population of London was "feebleminded" and that the percent was the same in America.

Investigations as to the mental status of the population of our larger American cities show a large percentage of persons, men, women, and children who are "not quite right" and may at any moment become subjects for our care, if not legal punishment...perhaps half a million tramps, cranks, and peripatetic beggars crawling like human parasites over our body politic... Handicapped by the vices of their inheritance they are simply not strong enough to keep up to the social, civil and moral ethic of the age, and as an inevitable consequence, just as water seeks its level, they drop back by degrees to become in turn deficient, delinquent, defective, and dependent. <sup>15</sup>

It is important to note that these sentiments were being made by the educated leadership of the American medical and legal professions. The author can only speculate what the attitude of the common person was toward persons with disabilities.

It was during this period that the Association discussed ways to eliminate the problem of the "feebleminded" from society. This approach was based on a growing assumption of a genetic basis for all "feeblemindedness." Sloan and Stevenson in their work, A Century of Concern: A History of American Association on Mental Deficiency 1876-1976, state that an example of the foundational principles of this philosophy and its modus operandi can be found in a paper entitled "Hints to the Officers of Institutions for the Feebleminded" by Jay Madison Taylor, MD, Philadelphia.

The paper epitomized the closed compartment type of logic which, on the one hand, pointed out a variety of causes for feeblemindedness which were not hereditary, and, on the other hand, assumed a genetic basis for all feeblemindedness. Taylor, for example, mentioned such things as underfeeding, moral and physical deprivation, cruelties practiced by thoughtless or brutal parents, adenoids, defective eyes or ears, and disturbances of the heart and circulation. Nonetheless, he concludes:

... And lastly, one word as to the value of castration. This is a most delicate subject, but some considerable experience gives me the conviction that often it is necessary to adopt this course, no matter if it be shown to be in a sense an evil. Assuredly the

<sup>&</sup>lt;sup>15</sup> Ibid., 391-393.

procreation of offspring from those of feeble minds is to be emphatically deplored. I might almost say it is never to be desired. If then, procreation may be laid aside, what is the value of the sexual instinct to those defectives? ... The conclusion seems clear, then, that it is wise, when in doubt, to remove the organs which the sufferers are unfit to exercise normally, and for which they are worse in the unnatural cultivation or use. On this point many prominent authorities are boldly advocating extreme measures of relief, of which castration is the chief.<sup>16</sup>

This attitude is important to point out. This genetic theory provided the scientific foundation for social segregation and sterilization of the "feebleminded." This foundation helped to usher in a dark period called Eugenics.

For us (people with disabilities) the Modern Era begins in the late 1800's, we see the attitudes of society toward the disable change. This period marks the rise of medicine, institutional care, and social Darwinism. All three lead to increased repression and even annihilation. Because (the) beggar was no longer accepted in civilized cultures, the Disabled were forced into freak shows, work house, or state run institutions. By being shut away, the disabled became feared and reviled. While Christian Charity led to the creation of state-run care facilities, social Darwinism lead to people questioning who should live. Eugenics rose in popularity and was explored by all countries until Germany displayed the graphic consequences of dismissing the unfit.<sup>17</sup>

When people understand what "Eugenics" is, they often wonder how intelligent people could possibly believe such ideas. The reality is that, to a great extent, this theory is the result of the philosophy and the social conditions of the times in which it was born. Applications of eugenics can still be found in current attitudes and in legislation currently being enacted, especially that which involves life and death issues. Legal decisions often take on a consideration of "quality of life" when it involves a person with disabilities. Consider the Terri Schiavo case. The attitude of "better dead than disabled" often underscores legal and ethical decisions.

<sup>&</sup>lt;sup>16</sup> Sloan and Stevens, p. 43.

Lydia Fecteau, *Disabled in the Modern Era*, 2/9/04 [essay on-line] (2004, accessed January 30, 2006); Available from http://caxton.stockton.edu/disability/ModernEra; Internet.

Garland E. Allan states that Eugenics is the result of the economic, social, and political context in which it blossomed. <sup>18</sup> It is a way to explain social problems. The movement began after the turbulence of the Civil War. American industry was rapidly expanding and, with the mechanization of farming, cities were growing rapidly. There was inadequate housing. Exploitation of workers led to the formation of unions. Starting in 1873, a series of depressions occurred over the next three decades. The birth rate was declining among the upper class while the workers were out-reproducing them. Add to this the influx of immigrants and the stage is set for the existing social policies, institutions and charities to be seen as inadequate in the face of the growing problem.

Eugenics had its roots in Darwin's survival of the fittest theory combined with Mendelian heredity. The basic premise is that we must be diligent to make sure humanity doesn't dissolve. The two main ways to accomplish that is eliminating defectives and controlling breeding. If this sounds like animal breeding, you are correct. Many of the early proponents of Eugenics took the theories from livestock breeding. America was the number one proponent of Eugenics between the late 1800's and the early 1900's.<sup>19</sup>

The American Eugenic Society was formed by Charles Davenport to promote the theories and legislation was enacted that controlled immigration, created marriage laws and encouraged the infanticide of defective babies. The goal was to prevent the gene pool from becoming further corrupted.

The proceedings of the American Association on Mental Deficiency show approaches that assumed the theories of Eugenics.<sup>20</sup> The solutions discussed during the meetings of 1895 to 1915 included control of marriage, sterilization, segregation, and

<sup>&</sup>lt;sup>18</sup> Garland E. Allen, *Social Origins of Eugenics* [essay on-line] (Washington University, N.D., accessed January 30, 2006); Available from http://eugenicarchive.org/eugenics/list2.pl; Internet.

<sup>&</sup>lt;sup>19</sup> Fecteau, 2.

<sup>&</sup>lt;sup>20</sup> Sloan and Stevens, 86.

even the suggestion of euthanasia. By 1915, eight states had enacted sterilization laws. The official ideology of the movement remained in effect until the Second World War.

The Eugenics Movement never really ended, but simply went underground. After the atrocities of the Third Reich were revealed, the official movement dissipated in America or, at least, evolved into a new form. America continued, and continues still, to follow a philosophy that treats persons with disabilities as second class. They are treated as expendable persons by applying different standards and code of ethics to them. Physician-assisted euthanasia often target persons with disabilities and is a new form of Eugenics that shows the "true" American attitude that it is better to be dead than disabled. The philosophy of Eugenics is, sadly, still very much alive and well.<sup>21</sup>

After World War II, an outward change of approach toward persons with disabilities occurred as the result of several events from unrelated sources although it was not a substantial cultural attitude shift. As mentioned, the atrocities of the World War II silenced the Eugenics movement. The African American civil rights movement had a significant impact on parents and advocates. In a parallel movement and greatly encouraged by the civil rights movement, persons with disabilities, parents, and advocates spent some thirty years advocating for equal rights realized, to a degree, by the enactment of *Americans with Disabilities Act* in 1991. Prior to this and of more importance, these advocates sued for the right to public education and Pubic Law 94-142 in 1976. In addition, prominent people in society, including President John F. Kennedy, openly admitted having a family member with severe cognitive disabilities. President

<sup>&</sup>lt;sup>21</sup> This statement can be documented by considering current statistics and cases. In addition to the Terri Schiavo, mentioned earlier, current statistics point out that over 80% to 90% of women who are pregnant with a child with the Down syndrome are encouraged and chose to have an abortion. Recently, a case involving a six year old entered the news when it was disclosed that the doctors had used drugs and surgery to stunt the growth of the child.

Kennedy's creation of the President's Committee on Mental Retardation and the Special Olympics program created a new awareness of the presence of persons with disabilities living in our society. One of the greatest sources of change, or perhaps shame, was the televised documented of abuses at Willowbrook State Institution located on Staten Island in New York City in 1970.<sup>22</sup> Despite others' efforts, it was only after Geraldo Rivera's report about Willowbrook in 1972 on behalf of WAB-TV in New York that conditions began to change. This event, along with increased awareness, ushered in the period of deinstitutionalization and the current approach of societal inclusion of persons with disabilities. Regarding the final years of the institutionalization period, Lydia Fecteau points out a chilling statistic stating that

Based of figures from the Center for Mental Health Services 1994 and statistics obtained from the 1995 Funk & Wagnall's "World Almanac and Book of Facts" Page 163: 'Between 1950 and 1964, more people died (in) the United States federal, state and county 'mental institutions' than the number of Americans killed in the Revolutionary War, the War of 1812, the Mexican War, the Civil War, the Spanish American War, World War I, World War II, the Korean War, Vietnam, and the Persian Gulf War combined.<sup>23</sup>

An important point is that the attitudes seen in this period and since 1880 toward persons with disabilities are still present. Attitudes of fear toward the disabled, seeing them as inferior and as the suffering ones are still present and can be seen in current laws and practices in our society. "Better dead than disabled" can still be heard in arguments for euthanasia, abortion, and considerations concerning their place in society. Persons with disabilities are still very much viewed as the "others." One example is that recently it was revealed that 80 to 90 percent of mothers who receive pre-natal testing and are

<sup>&</sup>lt;sup>22</sup> Despite the scandals in the 1960's and 1970's, Willowbrook was not finally closed until 1987.

<sup>&</sup>lt;sup>23</sup> Fecteau, 4. The author has attempted to verify this statement by acquiring this document. To date, he has been unable to obtain it.

determined to be carrying a child with the Down syndrome ehoose to have an abortion after receiving counseling by a medical professional.<sup>24</sup>

The historic and societal attitudes presented here represent the leaders in education, medicine and social sciences. In fairness, there were opinions that were in opposition to these theories. Many of the new approaches to persons with disabilities since the 1970's are actually old ideas reborn with new titles. In the mid-1890's special education classes for children with cognitive disabilities were started in public schools. The first such class began in Providence, Rhode Island in 1896. This movement grew until 1935. An early proponent of community-based services vs. institutional services, Charles Bernstein began community placement programs in 1907. This program lasted into the 1920's. With the Depression, many of the more innovative programs came to almost a complete halt. This halting of progressive supports demonstrates that negative public attitudes toward persons with disabilities come to the surface in challenging times.

Catholic ministry services for persons with disabilities were undertaken at different times in different dioceses. They are not well documented, and so they cannot be considered a "movement;" rather, they are seen as individual diocesan initiatives.

For example, in the Catholic Diocese of Cleveland ministry services for the Deaf and for the Blind began well before the inclusion movement. The Apostolate for the Deaf began in 1880 and the Apostolate for the Blind began in 1949. Finally, the Apostolate for the Mentally Retarded began in 1966 by uniting previously existing

<sup>&</sup>lt;sup>24</sup> Deirdre A. McQuade, M.A., M.Div., "Roe's False Freedom," *Life Issues Forum*, November 4, 2005 [journal on-line] (2005, accessed February 13, 2006); Available from http://www.usccb.org/prolife/publicat/lifeissues/110405.htm; Internet.

<sup>&</sup>lt;sup>25</sup> Sloan and Stevens. 297.

educational, social and religious programs together as official ministries that encourage the integration of persons with cognitive disabilities into the church. This last ministry is a good example of how ministries were developed by a diocese. The creation of the Apostolate for the Mentally Retarded was not a ministry of new services. As is typical in the development of ministries to persons with disabilities, this organization was originally the integration of previously existing ministries and services. In this case, the diocese combined a day elementary school for children with disabilities that had been operated by religious sisters in various basements of parish school buildings for years previously with a summer camp program that was provided by a group of lay men called the Raphael Society. A weekend retreat program that had been operated separately was added to initial services. All of these ministries started independently of each other and most were begun hy parents and advocates. In many areas of the United States, individual initiatives, such as these, pre-date the church's official orchestration of a diocesan program. As a result, it is difficult to determine when these ministries actually began. It is safe to say that initiatives began far earlier than the official church recognition of these ministries. 26

At various times in different parts of the country, schools were started for children with cognitive disabilities by various religious communities. Information concerning them can be found written in early publications on "special" education. One such book by Sr. Mary Theodore, O.S.F., gives a brief history of the St. Coletta Institute for Backward Youth, which opened in 1904 in Jefferson, Wisconsin. She states that

<sup>&</sup>lt;sup>26</sup> The author collected this information from various conversations over twenty years with Rev. Joseph D. McNulty, Director of Disability Ministries, Sr. Leonard Kelley, Program Director of the Outreach Program for the Mentally Retarded and William Tighe, Program Director of the recreation and camp programs for the Apostolate for the Mentally Retarded.

"...home care, physical comforts, and spiritual assistance adapted to the child's need" were offered to the children. <sup>27</sup>

approach toward persons with disabilities, began to change. After the war, with returning veterans with disabilities, American attitudes began to shift to providing care and rehabilitation for the veterans. Catholic Charities of New York City formed a cooperative venture with Jewish Family Services, the Veterans' Administration and the Community Service Society to meet the needs of returning veterans by assisting them in re-adapting to family living. These efforts had an impact on the attitude toward general population of persons with disabilities. Despite the lack of a unified movement, these examples demonstrate the hope that the church, in different diocese, extended to persons with disabilities.

In secular society, in different areas of the country, special education was resurrected, both public but more often private, until the passage of federal legislation made special education an obligation of the state under Public Law 94-142. As stated previously, with the scandals of the conditions of the institutions revealed at Willowbrook State Institution, deinstitutionalization began. Society's approach to the inclusion of persons with disabilities began to change by moving from institutional settings to fifteen, eight, six, and then four-person group homes. More recently, skill enhancement programs were offered to encourage community employment instead of separate sheltered workshops. Despite these positive movements, there is still a societal attitude of fear and the desire to build separate communities for persons with disabilities.

<sup>&</sup>lt;sup>27</sup> Sr. Mary Theodore, O.S.F. *The Challenge of the Retarded Child* (Jefferson, Wisconsin: Bruce Publishing, 1969), 18.

The work of several human service system developers, including Burton Blatt and Wolf Wolfensberger, indicates that persons with cognitive disabilities are seen as children, objects of pity, angels (above humanity), or subhuman (beneath humanity), i.e., "vegetables."

Jeannine Vogel, Edward Polloway and J. David Smith quote Bret Webb-Mitchell by stating that "many mainline denominations have eloquent position papers stating that all people should be welcome ... (but) individual congregations have been scandalously inhospitable to children with disabilities."

The historic causes and current attitudes are enough for the church to consider persons with disabilities as marginalized people. As such the church's social justice principles calls it to take action to integrate persons with disabilities into the church and society. Since the 1960's the disability movement has demonstrated the talents more than the needs that persons with disabilities can bring to the church.

# Social/Economic Position of Persons with Disabilities in American Society

In addition to history, the current social/economic position of persons with disabilities in society is important to note as a basis of social justice considerations that should be considered by church community. Persons with disabilities today live everywhere, in both rural and urban settings, though not equally. They come from every economic background, although the percentage of persons with disabilities is far higher among the economically disadvantaged living in mainly larger urban areas. It is difficult

<sup>&</sup>lt;sup>28</sup> Jeannine Vogel, Edward Polloway and J. David Smith. "Inclusion of People with Mental Retardation and other Developmental Disabilities in Communities of Faith," *Mental Retardation*, Vol. 44, Number 2 (2006), 100-111.

to describe this group as a whole, except in the area of quality of life, which impacts persons with disabilities as a whole. Some general statistics may be of assistance to describe their current sociological place in society.

The New Freedom Initiative<sup>29</sup> from President George W. Bush, reports the following general important statistics and conclusions:

- Fifty-Four million Americans live with disabilities, 20 percent of the U.S. population.
- Disability is not the experience of a minority of Americans. "Disability" is an experience that will touch most Americans at some point during their lives.
- Persons with disabilities are in the midst of a civil rights movement. There are many barriers to equality that face them daily. Almost half of these individuals have a severe disability, affecting their ability to see, hear, walk, or perform other basic functions of life.
- There are over 25 million family caregivers and millions more who provide aid and assistance to persons with disabilities.

The *New Freedom Initiative* goes on to draw the following major conclusions from the statistics the government has collected.<sup>30</sup>

- Americans with disabilities have a lower level of educational attainment than those without disabilities.
- Americans with disabilities are poorer and more likely to be unemployed than those without disabilities.
- Finally, the report concludes that too many Americans with disabilities remain outside the economic and social mainstream of American life.

Adding to these findings, with data collected from the 2000 census survey, the U.S. Census Bureau released a special report on *Disability and American Families*. <sup>31</sup> The Census Bureau, which issued its report in July 2005, drew many conclusions from

<sup>&</sup>lt;sup>29</sup> George W. Bush, The *New Freedom Initiative*, February 1, 2001 [publication on-line] (2001, accessed January 17, 2004); Available from http://www.whitehouse.gov/news/freedominiliative/freedominiliative.html; Internet.

 $<sup>^{\</sup>rm 30}$  For additional selected statistics from The New Freedom Initiative that support these conclusions, see Appendix B.

<sup>&</sup>lt;sup>31</sup> U.S. Census Bureau, *Disability and American Families* [report on-line] (N.D., accessed March 16, 2005); Available at http://www.census.gov/prod/2005pubs/censr-23.pdf; Internet.

the data the agency collected related to the prevalence of disabilities in American families. The data was collected from six questions on the Census 2000 long form, which includes questions on the short form and additional questions relating to social, economic and housing characteristics. Among the bureau's major findings and conclusions are the following points:

- "Disability" is a prevalent and common issue among families. Of the total of 72.3 million families that were counted, it was found that nearly 28.9 percent of them (about 2 in every 7 families) reported having at least one member with a disability. Disability rates varied among different racial groups but were prevalent in all groups.
- One in every three families with a female householder with no husband present reported members with a disability. <sup>32</sup>

This last finding is an important one on which to comment. The author feels that it underscores that the presence of disabilities impacts the entire family and may be often the cause of a broken marriage. Moreover, "disabilities" is a particular female issue. It is often left to the female to be the sole parent for children with disabilities.

The Census Bureau's report adds the following conclusions:

- The Census Bureau's report confirmed that persons with disabilities and families with a person with a disability were more often economically disadvantaged than their peers. They state that families with members with a disability had lower median income than other families. These families were less likely to receive an income and usually received Social Security income and public assistance. As a result, these heads of households were less likely to be employed. The report points out that persons with a mental disability had the lowest employment rate (34.2 percent) and the largest proportion of people not in the labor force (60.8 percent).
- The report concludes that, in every state, families with a member who have a disability were more likely to live in poverty.

Overall, these findings point out that families raising children with a disability are more likely to live in poverty than other families raising children and that these families

<sup>&</sup>lt;sup>32</sup> See Appendix C for more findings from the 2000 Census Survey.

often faced many other issues, other than the "disability" issue, that impacts their quality of life.<sup>33</sup>

The latest *National Organization on Disability/Harris Survey of Americans with Disabilities* reveals that persons with disabilities are at a critical disadvantage compared to other Americans in ten key areas of life.<sup>34</sup> Continuing a trend, the survey found slow and modest progress in the indicators, which Harris has been tracking since 1986.

The ten key areas of life measured include employment, income, education, health care, transportation, socialization, going to restaurants, political participation, life satisfaction and optimism for the future, and assistive technology. Pastorally, the tenth area is the most important statistic for this work. It is entitled "Attendance at Religious Services."

[The report notes that] People with disabilities continue to be less likely to attend religious services at least once per month when compared to people without disabilities (49% versus 57%, respectively), despite the fact that people with and without disabilities are equally likely to consider their religious faith important to them. More than 8 out of 10 people with (84%) and without (85%) disabilities say their faith is important to them and exactly 57% of both groups describe their religious faith as *very* important.

As with many of the indicators, the degree of one's disability has an impact on how often people worship. People with slight disabilities attend religious services more often than do people with very severe disabilities (56% and 44%, respectively). This difference is more pronounced today than it was in 2000, suggesting that more needs to be done to remove architectural, communications, and attitudinal barriers that prevent people with disabilities—especially people with severe disabilities—from regular attendance.

Interestingly, the degree of one's disability also plays a role in the importance of religious faith. People with very severe disabilities are more likely to say their

<sup>34</sup> David Krane and Kristina Hanson, Senior Research Manager. *NOD/Harris Survey of Americans with Disabilities* (New York: Harris Interactive, 2004), 81.

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<sup>33</sup> U.S. Census Bureau.

<sup>&</sup>lt;sup>35</sup> Ibid., 81 ff.

religious faith is *very* important to them than are people with slight disabilities (65% versus 53%, respectively). Once again, religion's importance to this group suggests that their low level of attendance is not due to a lack of interest, but possibly to various barriers to participation.

Trends: Attendance at religious services has fluctuated for people both with and without disabilities since 1986. The most considerable gap in attendance at religious services at least once per month was in 2000, at 18 percentage points. Since that time, the gap has narrowed significantly to 8 percentage points.

There has been progress in this area. In 1994, the Harris Survey reported that 68% of persons with disabilities considered their religious faith to be "very important." Attendance at religious services was about ten percentage points less for persons with disabilities than for the person without disabilities. However, persons with disabilities were nearly twice as likely (39 % to 22%) never to participate in religious services. Overall, the survey points out that more needs to be done on the part of churches.

In this general profile of persons with disabilities, the Harris Survey points out one important item. No matter what race, socio-economic class or type of disability a person has, worship is as important as to any other group in our society. In fact, Harris points out that worship is more important to persons with more severe disabilities. The people who are often the ones who are not able to participate fully are those who most wish to be present to worship with a community. Pastorally, this is an important consideration. It calls for a ministry of outreach to persons with disabilities and their families who are also impacted by the disability. More than this effort, it calls for an active advocacy on the part of the church to integrate persons with disabilities. The conclusions for architectural renovations to a church are very obvious. These statistics

<sup>&</sup>lt;sup>36</sup> Ibid., 81.

<sup>&</sup>lt;sup>37</sup> Janet Miller Rife and Ginny Thornburgh. *From Barriers to Bridges: A Community Action Guide for Congregations and People with Disabilities* (Washington: National Organization on Disabilities, 1996), 50.

only explore the external reality of life for persons with disabilities. More basic than external modification to a building is the inner transformation of creating a welcoming community that is ready to integrate the stranger and those who are considered *different*. This call fits squarely within the social justice mission of the church.

## Words as Acts of Oppression

Labels have always marginalized people from the dominant group in society. The majority oppress individuals by giving them names to separate them. Persons with disabilities, as seen in history, have been labeled feeble-minded, idiots, mutes, deaf and dumb, cripples, and retards, to name a few. The point is that the terms we use to describe people often express an implicit or explicit message. The message, the meaning, is our internal attitude towards the people the words represent. Sensitivity to the terms we use is important to the liberating process. In the disability movement terms have become very important. They are a first step to recognition of the person.

People are at times confused at the seemingly constant change of terminology used to describe a person with a disability. This difficulty is especially true of persons with cognitive disabilities. Since the 1960's, and much more frequently in recent years, terms have replaced previous labels that had only been in place for a few years. The most important point is "people first" language.<sup>38</sup> The person with a disability is a person first. The disability is a secondary consideration. Sensitivity in language is a beginning point in integrating the marginalized in the community. The church must be aware and utilize

<sup>&</sup>lt;sup>38</sup> "People first" language is accomplished by always placing the person's name before the descriptive term. For example, "person with a cognitive disability" is preferable and less insulting than the "cognitive disabled person." This is a way for the speaker to remember that he or she are referring to a person and not a condition. There are exceptions. Persons who are deaf from birth often refer to themselves or their community as "The Deaf" (capital "D").

only appropriate disability language in their words and the interpretation and expression of scripture.

Harold Wilke speaks of the negative attitudes that church communities display toward persons with disabilities.<sup>39</sup> They are subtle but increase the marginalization of this second-class group. The negative attitude is often expressed in various ways. There may be outright rejection. The person may be put in the back of churches, meetings, or schools making them feel secondary. The church might display an over acceptance of the person. This effort seems contradictory but when a community swarms over persons with disabilities, it can seem as if they are the token or prize in the community. The third approach can be one of sanctimonious exhortations in which persons with disabilities receive virtual verbal abuse. Welcoming the person with disabilities is welcoming the person with talents, gifts and needs. Our actions as well as our words can oppress as well as free.

Even currently acceptable terms can be oppressive, even if in a subtle way.

Consider the term "inclusion." Inclusion is the currently accepted word for the complete integration of persons with disabilities into society and, pastorally, into the church. The author has a personal bias against this term. First, it connotes a patronizing attitude on the part of the majority to include someone as if we (the majority) were giving them something that was not rightfully theirs. Second, if people can "include" they can also "exclude." There is a connotation in the term that a person has the choice almost whether or not to include another. For these reasons, the author uses the term "integrate" rather than "include." Once the church has integrated persons with disabilities into its

<sup>&</sup>lt;sup>39</sup> Harold H. Wilke, Creating the Caring Congregation (Nashville, Abingdon Press, 1980), 36ff.

community, there is no going back. We will be different, but better. We will be more completely the Body of Christ on earth.

#### Ecclesiology and the Place of Persons with Disabilities

Thus far we have considered the history, social conditions, and societal attitudes toward persons with disabilities. Based on these considerations, it is obvious that persons with disabilities fit the category of the *poor*, people truly marginalized by those who form the majority of society. The social justice principles of the church are enough to call for a special consideration of these individuals. The principle of *preferential option for the poor* alone could be used as a basis for the integration of persons with disabilities into church and society. As vulnerable or marginalized members of society, persons with disabilities present a moral claim on the conscience of our church as well as our society.

However, this basis for integration is not sufficient. It could easily be seen as an act of charity. It is justice and not charity that must be the basis of integration or the result is token membership. The church's social justice principles form a part of the foundation calling us to assist persons with disabilities to be a complete part of the church community. On its own, the principle falls short of the realization that it is God and not our charity that calls persons with disabilities to membership in the church. It is our recognition of the "personhood" of persons with disabilities and their call to discipleship in the church that is more fulfilling.

Up to this point, this theological/theoretical section has concentrated on external forces and attitudes that have created a milieu of alienation in our society toward persons with disabilities. Now this paper will consider the church and its intrinsic ecclesiological call to integrate persons with disabilities. Ecclesiology could be described as "the branch of

theology that is concerned with the nature, constitution, and functions of a church."<sup>40</sup> It is the church's definition of who it is and how does it function in the world. The church's ecclesiology (the functioning model or paradigm) has been important throughout history as to how the church carries out its mission at that time in history. Therefore, it is important to consider briefly a model or paradigm of the functioning church that includes all people and reaches out to the marginalized.

The Second Vatican Council and the resulting ecclesiology produced various paradigms of the church. Avery Dulles expounded on the Council's ecclesiology by describing the church in terms of "models." Each model constitutes one facet of the church as *Mystery*. Many of these models could be employed as one that includes all people.

This author will concentrate on two models that uniquely express the need for the integration of persons with disabilities into the church community. The first speaks to the church community's call, its responsibility to integrate. The second will reflect on the essential call of persons with disabilities as people made in the image of God, to be full participants in God's Kingdom, which assumes the right of membership and participation in all aspects of church life. The first model expresses the church's call to include the marginalized. The second model expresses the intrinsic dignity of persons with disabilities as people created in God's image and called, as we all are, to the ministry of service to others. The latter model is more essential to this consideration since in it, the church is responding to a people already *called* by God. It is the church's recognition that their presence in the church community enhances our understanding of the ever-

<sup>40</sup> Dictionary.com, [publication on-line] (Lexico Publishing Group, LLC., 2007, accessed March 3, 2007); Available from http://dictionary.reference.com/; Internet,

forming Kingdom and all of the various roles in it. This awareness adds to our understanding of God's will.

#### The Church as Servant

Avery Dulles speaks of a model that can be inclusive of all people, within and outside the present community. The model must be "deeply rooted in the corporate experience of the faithful." The "Servant Church" presents a model of church that reflects social justice principles, but goes beyond them, as well. This model describes a church that is more than reaching out to the marginalized. All members, once full participants, become the "servants" to others. In this way, the marginalized, by becoming part of the church community, change the membership into a wider serving community. It changes the essence of the church on earth. This revitalized church reaches out to others as the sacrament of salvation.

This discussion is an important distinction of the Servant Model and a crucial consideration pastorally. Since the 1960's, as the disability rights movement developed, there has been a shift from a *mission to* persons with disabilities to a *mission with* persons with disabilities. The emphasis of *with* is important in the servant model. The model of church calls us to integrate and to serve, but it also moves the church to incorporate the talents and the individual charisms of persons with disabilities into the ministerial aspects of the church. This process is how the church becomes a servant to persons with disabilities. This model is accomplished by reaching out to them as now marginalized, and then enabling them to participate in the ministries and leadership of the church to

<sup>&</sup>lt;sup>41</sup> Avery Dulles, "Imaging the Church for the 1980s," *A Church to Believe In, Discipleship and the Dynamics of Freedom* (New York: Crossroad Publishing Co., 1982), 16.

others in need. Quoting Douglas Horton, in *Vatican Diary*, Harold Wilke states that at Vatican II, Popc Paul VI began to move toward a Gospel based on a "mission with" philosophy.

[At the closing session, in 1965, the Pope gave a]...special word of recognition...to several groups in the human family...On the one hand to receive that word were government leaders, intellectuals, artists, women, workers, youth, and finally, two persons with physical impairments—a paraplegic and a blind man." (Douglas Horton, Vatican Diary, Philadelphia: United Church Press, 1965.)<sup>42</sup>

However, it was other religious traditions<sup>43</sup> that first began to make church statements concerning persons with disabilities. Interestingly, Dr. Vischer and Dr. Gerald Moede, who participated in possibly the first church statement by the Faith and Order Commission of the World Council of Churches in 1971, were both present when Pope Paul made his remarks. This statement is important to point out because it is demonstrates the "scryant model" of church.

In the church's enthusiasm to reach out as "servant," there is a word of caution.

All models are only a facet of this mystery we call church. As Dulles pointed out in 1982, the "Church as Servant" model could make the church nothing more than any other humanitarian activity. The activity of the church must be deeply rooted in the gospels, and any social outreach must be done with the ministerial goal of drawing all people to Christ.

To accomplish its call, the servant church must be in dialogue with the world.

There is an interplay in which the church stands, not as the sole keeper of truth that is

<sup>&</sup>lt;sup>42</sup> Harold H. Wilke, 47.

<sup>&</sup>lt;sup>43</sup> In this work, "Other religious traditions" refers to individuals who are not Roman Catholic.

<sup>&</sup>lt;sup>44</sup> Avery Dulles, "Imaging the Church for the 1980s," 16-17.

shared by its own members, but as the servant ready to be of help to all people. In this model the church is the beacon of the Kingdom reaching out to those in need. In this model the church must study the signs of the times (*Pacem in Terris*) and discern the action of the spirit in the world. The church's role is to associate through its members with movements working for peace, justice, liberation, and reconciliation in the world. Richard Cardinal Cushing states that

Jesus came not only to proclaim the coming of the Kingdom, he came to give himself for its realization. He came to serve, to heal, to reconcile, to bind up wounds. Jesus, we may say, in an exceptional way, is the Good Samaritan. He is the one who comes alongside of us in our need and in our sorrow; he extends himself for our sake. He truly dies that we might live and he ministers to us that we might be healed. 45

The church as servant model is one that promotes justice and equality for persons with disabilities. In this model the church recognizes the movements that have occurred in the lives of persons with disabilities. It actively advocates for the basic human rights and moves further to integrating persons with disabilities into the life of the Christian community. The call to include the marginalized is a call for the church to integrate people as a sign of social justice and recognition of their dignity as children of God. True justice always implies action. Justice in action is an essential act of advocacy.

Pastorally, the church should continue to consider how it may be penalizing persons with disabilities at the points of Baptism, Confirmation and Eucharist and to admission to other offices and orders of the church. What the servant model calls for is for the church to understand actively and break down the fear of persons with disabilities and replace the fear with genuine love and acceptance. The greatest challenge for the church is to discover new ways to minister to people who many seem different from the

<sup>&</sup>lt;sup>45</sup> Avery Dulles, *Models of the Church*, 86.

typical parishioner. The servant is open to a change to assist in the widening of the Kingdom of God.

#### The Church as the Community of Disciples

The servant model of church is incomplete if the accent remains on the church and its call to integrate the marginalized. The call must be balanced with recognition of the person who is already called. The church is simply responding to the reality of God's action in a person's life. Dulles' insights on models bring us to the conclusion that the crucial point of reference in any paradigm of church is the person, his or her call and then the church's response to assist in the formation of faith.

Up to this point, this chapter has dealt with the church's call to integrate. It has accented the church's call to practice social justice and to be the servant. From this point, the attention will shift to the person who is called and will consider this call as one to equal discipleship, equal participation and sharing equal personhood in the church. An appropriate model of the church should reflect this recognition. All of Dulles' models contain this awareness. However, there is one model that makes this recognition the essence of their paradigm. The church as the *Community of Disciples* shifts the attention from the church *per se* to the person and his or her call from God.

Considering persons with disabilities as members of the community of disciples is an important aspect for the complete integration of persons with disabilities into the life and ministries of the church. This model affirms their complete personhood and call from God to live a life of grace in the Spirit. The call is to a people "as they are," persons with different needs, but possessing different talents that add to our understanding of the human being. It is the call issued to each of us to serve as disciples. Persons with

disabilities teach other ways of viewing personhood and God's action in the world. Their presence as equal disciples adds to the tapestry of the Kingdom. The church's recognition of this reality compels it to respond to the person already called. It further compels the church to reach out to those who do not yet realize their call, their giftedness and their rightful place at the table.

The community of disciples model is closely connected to the servant model of church and also reflects the social justice teachings of the church. The foundation of this model is the recognition, before all else, of the "dignity of the person" or the recognition that the person is created in the image of God. In this model is the call of all people to full participatory membership. This call includes persons with disabilities. As people made in the image of God, the person has a right to full participation in God's Kingdom, assuming the right of membership and participation in all aspects of church life.

According to Dutch theologian Edward Schillebeeckx, human dignity, the basis of discipleship, is one of the important themes of Vatican II.

The Second Vatican Council showed another face of the church; at least in theory it heavily corrected the previous image of the church....Even before mentioning church ministries, this council defined the church as the people called together by God. In it all believers are equal, believing subjects of equal worth 'living from the Spirit,' free children of God. 46

Are persons with disabilities really equal in dignity to the typical individual? This assumes that they share equal personhood with others. Society's behavior and attitudes have not demonstrated this realization.

<sup>&</sup>lt;sup>46</sup> Edward Schillebeeckx, Church: The Human Story of God (New York: Crossroad, 1990), 207.

#### Personhood

Why include a section on personhood in writing such as this? Many authors assume the personhood of individuals with disabilities, or simply acknowledge it, and move into practical matters. This work deals with personhood because it is essential to understanding persons with disabilities' full equality in the church.

The theology of the church as the community of disciples calls the church to an awareness that all members share different ministries to build up the Kingdom of God. All are equal in their discipleship because they are created in "God's image." This is an easy statement to make, but what about persons with severe cognitive or physical disabilities that are often excluded or, at least, separated from the general community? Does the church view them as sharing equally in the right to discipleship?

The church does believe that persons with disabilities are full persons by reason of their baptism. Baptism is one sacrament that is not refused because of the existence of a disability. This acceptance of the person expresses the church's belief in personhood. Canon Law states that, "By baptism one is incorporated into the Church of Christ and is constituted a person in it with the duties and rights which are proper to Christians in keeping with their condition..." In other words, one becomes a "person" through Baptism. In this description all persons with or without disabilities are equal members in the church. Yet another consideration is needed to see a wider view of the personhood of all people, even those outside the church's community. The question is, what makes all human beings different and unique in God's creation, or put another way, how is a person "made in the image of God?"

<sup>&</sup>lt;sup>47</sup> Canon Law Society of America, "Physical and Juridic Persons" (Can. 96 – 123), [publication on-line] (Washington, DC, N.D., accessed March 17, 2006); Available from http://www.vatican.va/archive/ENG1104/\_INDEX.HTM; Internet.

Catholic theology has always been informed by philosophy. Philosophy has viewed the essence of being a person as possessing cognitive functioning, the ability to self-reflect, and/or the ability to create. These have been most frequently used to separate the human from the rest of creation. However, a person is more than just an intelligence score. Contemporary works on theories of learning such as multiple-intelligence or emotional intelligence point out other areas that constitute attributes of a person such as the ability to relate to others.<sup>48</sup>

What about the person with severe or profound levels of cognitive disabilities?

Often society's definitions do not seem to apply, because the abilities of these individuals to rationalize or to create are not apparent to the rest of us. Does this mean that these individuals do not possess full personhood? Few contemporaries, if any, would agree with this sentiment. Considering the history of the treatment of persons with cognitive disabilities and society's current attitudes toward them, there exist common beliefs that these individuals are not "complete" persons. The church's pastoral practices have also, at times, reflected this attitude. It is important to have a solid foundation for the equal personhood of human beings, or integration could become simply an act of charity. This approach leads to patronizing persons with disabilities, actually separating them even more from the rest of the community.

The work of Trinitarian theologians has added to our thinking about our concept of personhood. The use of the word "person," in referring to the Trinity, is always analogical. From the earliest days, since the concept of Trinity was introduced, there has been a discomforting in the use of the word, "person." The discomfort is that it is too

<sup>&</sup>lt;sup>48</sup> To review other aspects, other than intelligence, that contributes to a concept of "personhood" see: Daniel Goleman, *Working with Emotional Intelligence* (New York: Bantam Books, 1998).

easy to describe the Trinity as three actual persons. The importance for this paper is that our belief in the Trinity of Father, Son and Holy Spirit gives a way of thinking about the human person as created in God's image. This belief presents a way to include all people as made in the image of God. This belief challenges us to accept individuals as created by God as they are, with or without disabilities.

The Trinity is a belief that resulted from Christians' reflection on the self revelation of God in light of their experience of the abiding presence of the Son and the Holy Spirit in the early church. It moved people to think differently and pray differently, praying in Christ's name through the power of the Holy Spirit. Its basis was in experience and practice. The theology of the Trinity evolved later over centuries of debate. Over those years, the belief began to hold a minor position in practical theology.

Karl Rahner has written that, "We must be willing to admit that, should the doctrine of the Trinity have to be dropped as false; the major part of religious literature could well remain virtually unchanged." In the last thirty years a re-interest in this dogma has produced a re-vitalized theology. This theology has enhanced its meaning for us, particularly here, for its meaning of personhood. Some contemporary thinkers like Catherine LaCugna have come to the conclusion that the Trinity is a practical doctrine. LaCugna's theology on the Trinity has revitalized contemporary interest in the practicality of this belief in reference to Christian living. She built on the work of Rahner, developing her theology by returning to the Cappadocian Fathers' emphasis on relationship. Living in relationship with others is the fundamental attribute of being human. One who is "for others" and "with others" is in the image of God.

<sup>&</sup>lt;sup>49</sup> Karl Rahner, *The Trinity* (New York: Herder and Herder, 1970), 10-11.

LaCugna offered several applicable insights on relationship that speak to the equal personhood of all members of the church. She states that "...the Cappadocians argued that God's Fatherhood, God's Godness, must always be thought of relationally, one person in reference to another." <sup>50</sup> Analogously, the personhood of the Trinity is one of relationship. The members of the Trinity are "for each other" and act only in relationship to each other. Through their actions in salvation history God revealed God's self as God "for us" as a people. The key word is relationship. In LaCugna's theology, the doctrine of the Trinity reveals a different understanding of "being created in the image of God." The fundamental God-like characteristic of the human person is that we are "for each other and for God." We are able to live in relationship to others and to God.

What we know of God is that which has been revealed by God's activity in salvation history. This activity culminated in Christ's words and actions. Our knowledge of this experience was expressed through a believing community whose goal was fundamentally to keep the memory of Jesus alive. What is revealed and expressed in our creed is that the Father, the Son and the Holy Spirit are in continuous relationship to each other and to us.

We say that people have dignity because they are created in the image of God.

By this statement, we are expressing a belief that what makes a person human is not his or her ability to think, reflect or create. It is their ability to be in relationship with another, to be "for each other and for God."

[What is expressed in Trinitarian Personhood] is a view of human personhood thoroughly rooted in the personal mystery of God disclosed in Jesus Christ through the power of the Holy Spirit. Just as God is personal, that is, God exists in relation and would not exist at all if not in relation (Father, Son, Holy Spirit),

<sup>&</sup>lt;sup>50</sup> Catherine Mowry LaCugna, *God for Us: The Trinity and Christian Life* (New York: Harper San Francisco, 1973), 394.

so human beings are personal, human beings exist only in and through relation to another, others, and God. In this view, the human person does not exist as an individuated nature, or a subsistent self which is antecedent or prior to self-expression...The understanding of human personhood rooted in Trinitarian ontology of personal relation is one that enables us to see that we are what we are only insofar as we are from others and for others.<sup>51</sup>

LaCugna summarizes the consideration of personhood as relational.

[She states that] every human being, and indeed every creature, has its origin in a person who by definition is not solitary but in relationship with another...we are persons in relationship to another...we are persons by virtue of relationship to another. Persons know and are known, love and are loved, and express themselves in freedom. To think of a person without thinking of that person in relationship to another person defeats what it means to be a person. <sup>52</sup>

Another theologian, Michael Downey, applied LaCugna's insights to persons with cognitive disabilities. His importance to this present work is that he presents, not just a theology, but an expression of his experience from working and living with a L'Arche Community. Downey states that "all authentic Christian spirituality is ipso facto Trinitarian...the doctrine...with its far reaching practical implications, constitutes the heart and soul of Christian spirituality." <sup>54</sup>

LaCugna expresses what we mean by person from a theological perspective.

Downey adds his practical experience applying the theology to persons with disabilities.

His significant contribution is that he applies LaCugna's theories to persons with severe cognitive disabilities, and concludes that, despite their cognitive limitations, these

<sup>&</sup>lt;sup>51</sup> Michael Downey. "Trinitarian Spirituality," Eglise et Theologie, 24 (1993): 113.

<sup>&</sup>lt;sup>52</sup> Catherine Mowry LaCugna, "The Practical Trinity," 681.

<sup>&</sup>lt;sup>53</sup> L'Arche Communities, founded by Jean Vanier in France in 1964, bring together people, some with developmental disabilities and some without, who choose to share their lives by living together in faith-based communities. The first L'Arche community in the United States was founded in 1972, and there are now 15 communities nationwide. For more information, *visit* http://www.larcheusa.org.

<sup>&</sup>lt;sup>54</sup> Michael Downey, ed. And Catherine Mowry LaCugna, "Trinitarian Spirituality," *The New Dictionary of Catholic Spirituality* (Minnesota: Liturgical Press, 1993), 968.

others and to God. In this way they demonstrate their personhood as created in the image of God. He states that the person with disabilities simply offers an altogether different view of what it means to be a person, "once person, not substance, is taken as prior and ultimate." Setting aside the measurement against which we judge people as to their worth, we can look to persons with disabilities as our teachers of what it means to be a person. This approach to personhood is not built on a pre-determined definition of human nature, but "based on the equality of persons who are equal because they are theonomous, from God, in God, for God. This is a relational God, a God who is for us."

Trinitarian theology presents the foundation that calls the church to view all people as capable of being called to discipleship because of their complete personhood in the image of God. Persons with disabilities, including those with severe cognitive disabilities, are equally called to be part of the community of disciples. It further challenges us who are called to be pastoral leaders, to re-examine our approach to persons with disabilities and our belief as to their "worthiness" to serve as ministers, as leaders, as servants to others. Approaching a person as an equal is a challenge when one is used to approaching him or her as a person in need of our charity, sympathy, or worse, pity. This challenge is one that our church must continue to face as more persons with disabilities present themselves as members of the community of disciples, equal in their God-like personhood and dignity.

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<sup>55</sup> Downey, "Trinitarian Spirituality," 118.

<sup>&</sup>lt;sup>56</sup> Ibid., 118.

[Catherine LaCugna states that] In Jesus Christ, God heals divisions, reconciles the alienated, gives hope to those who have none, offers forgiveness to the sinner, includes the outcast. In the end, God's love and mercy are altogether inclusive, accepting the repentant master as well as the repentant slave. If anyone were to be ultimately excluded from the reign of God it would be because he or she had set himself or herself as the final criterion of who should be included in God's reign. Still, the exclusion of even a single person is contrary to God's providential plan.<sup>57</sup>

Persons with disabilities possess the same rights as other members of the church to participate in all aspects of church life. As created in the image of God, persons with disabilities have a calling into the life of discipleship in the church. The church, recognizing the equality of persons with disabilities, has a call to reach out to integrate persons with disabilities, not just as members, but as fully participating and active members. Section One dealt with fundamentals and foundational issues for the integration of persons with disabilities into the church. Section Two will deal more with pastoral practices that assist persons with disabilities to begin or to continue their journey to a discipleship that serves others to the glory of God through Jesus Christ in the Holy Spirit.

## Section 2: Sacramental Integration as the Starting Point for full Participation in the Church

Most people enter the church and continue their life journeys marking crucial life events by celebrating the sacraments. The sacraments build the community of disciples who are seeking a fuller relationship, individually and as a community, with God. At such important spiritual moments in which the community is formed and re-formed, and traditions are handed on, special consideration should be given to sacramental access for persons with disabilities. However, it is the author's experience that, at the point of receiving a sacrament, or even participating in it, the persons with disabilities are at times

<sup>&</sup>lt;sup>57</sup> Catherine Mowry LaCugna, God for Us: The Trinity and Christian Life, 388.

excluded because of some limitation, whether cognitive or physical. The Sacrament of the Eucharist is the most important consideration here. Eucharist is the summit of all sacraments. The reception of the body of Christ is not only the finality of the rite of initiation, but it also is the sacrament that follows us through life creating the community of believers on the road to the Kingdom. The author has experienced that it is this sacrament that is most often denied due to a perceived limitation on the part of a person. For this reason, this sacrament deserves special consideration in this paper. In this sacrament, all of our beliefs come together, and it is in this context that we can assist persons with disabilities to access church as equal members.

#### Current Pastoral Obstacles in The Reception Of Eucharist

The issue of access to the Sacrament of Eucharist for persons with disabilities can be seen as a pastoral issue. Overcoming accessibility and attitudinal barriers may work well for some who are Blind, Deaf, physically challenged and those who have a mild to moderate cognitive disability. However, when a family wishes to have a person with a severe cognitive disability participate in Eucharist, applications of theologies can become an obstacle to the reception. How can a person who is so cognitively delayed assent to the real presence? How can they communicate their understanding of Eucharist? At this point, the person is often refused Eucharist because of their inability to enunciate an understanding of transubstantiation in a traditional manner.

There is a pastoral desire to welcome persons with disabilities into the church as full members. Without a theological foundation, the inclusion of persons with disabilities in the sacraments can seem more an act of charity than a community celebration of a sacrament that allows people the ability to deepen their relationships with God and to

answer the call from God. The universal call to holiness of Vatican II was extended to all people, including persons with disabilities.

### An Understanding of the Real Presence in Eucharist

Since the Council of Trent, the normative theological explanation of the Eucharistic action has been defined in the Catholic Church as "transubstantiation." One obstacle for persons who are cognitively delayed has often been their inability to express what is taking place in the bread and wine in ways that we are familiar with.

It must be said, prior to considering different understandings of Eucharistic presence, that the focus of the Eucharistic celebration was not always the elements themselves and knowledge of "what was going on in the bread and wine." Kevin Irwin, quoting Norman Tanner, presents a case for this view.

[In the patristic age, the] main concern was with the people present at the Eucharist; the medieval councils and Trent turned their attention towards the priest, the objects used in the Eucharist and especially toward the presence of Christ; Vatican II returns to the concern of the early church for the people present, though with rather different interests in mind.<sup>58</sup>

Irwin points out one important consideration. The fact is that throughout its history, the church has reassessed its Eucharistic doctrine at different periods because of the specific needs of that particular age. Recalling this fact is not to downplay the theology of transubstantiation. The point here is to keep the theology in the context of a far more diverse understanding of Eucharistic presence. Current Catholic theology emphasizes transubstantiation as being always at the heart of understanding the Eucharistic action. However, other ways of understanding have been presented to enhance the meaning of transubstantiation. They present other dimensions of Christ's

<sup>&</sup>lt;sup>58</sup> Kevin W. Irwin, *Models of the Eucharist* (New York: Paulist Press, 2005), 252.

action in the Eucharistic action.

Edward Schillebeeckx states that "The real concern should not be one of a correct theological explanation of the *res et sacramentum*, the real presence of Christ in these *sacramenta-signa*." The issue should be a consideration of the final outcome of the *sacramentum* (the consecrated bread and wine). *Res et sacramentum* is a means to an end. The end of the action is *res* sacramenti, "...the *communion ecclesiastica*, that is, the unity of the mystical body: the life of the community in Christ and, for the individual, the life of Christ in his soul, manifesting itself by an intimate sweetness, the 'dulcedo eucharistica." In other words, the issue is about what the Eucharist "docs." The end of the sacrament is *communio*.

Some pastoral leaders seem to stop with the *res et sacramentum* in their concern for a proper understanding of Eucharist. *Res sacramenti* has often been ignored in pastoral practice at the level where the focus seems to be more on transubstantiation as meaning only "real presence." What actually is taking place in the Eucharistic action (*res et sacramentum*) is known in the mind of God. It is only by faith that we come to believe what has been revealed. What is reciprocated and understood as to the meaning and purpose of the sacrament is important, along with a belief in the real presence. This purpose might be the element of understanding for persons with cognitive delays. The "significance" or "specialness" of the sacrament for them may be discernable.

For the first twelve hundred years of the church, transubstantiation was not a defined explanation of the sacrament. The Eucharist's meaning to life and to the building

<sup>&</sup>lt;sup>59</sup> Edward Schillebeeckx, "Transubstantiation, Transfinalization, Transignification," *Living Bread, Saving Cup*, R. Kevin Seasoltz, O.S.B., ed. (Collegeville, Minnesota: The Liturgical Press, 1987).

<sup>&</sup>lt;sup>60</sup> Ibid., 186.

up of the community were understandings that came from the spirituality of the community. Religious leaders who minister to persons with cognitive disabilities often have experienced the meaning of Eucharist "expressed" in ways that demonstrate a fuller appreciation of the meaning than just "real presence." Persons with cognitive disabilities can express the meaning of the sacrament in ways that demonstrate an insight into the end of the sacrament, the building of the community. Their understanding can be prophetic to the entire community. As such, their faith enables them to stand as prophets calling the community back to the essence of the church's beliefs.

Darren (not his real name), an adult with cognitive disabilities, first came to St. Augustine Church, Cleveland, around January, 2002. He was a student of mine both in high school and at a continuing adult education program. He had attended dances, socials, and summer programs offered by our Diocese but would eventually drop away from each after a while. When first attending St. Augustine, Darren sat in the back. But after several weeks he sat closer and closer till he took up his permanent front row seat. Shortly after this he announced to me that he wanted to become a Catholic. He said, in his own way, that he wanted to be close to Jesus and that he felt "at home" in this church. After attending a special RCIA designed for him, he received Baptism, Confirmation, and Eucharist at the Easter Vigil Liturgy. As my wife, Jill, and I stood with him during his Baptism and Confirmation, for he had asked us to be his sponsors, there was a keen sense of the presence of God calling to one of God's children to come and take his place at the table as an active member. As he faced the congregation there was not a face without a smile or an eye without a tear. It was a moment that his faith showed God's love to all of us... This theological breakthrough, this "theologia prima" makes the Eucharistic Celebration more than just a ritual or just a prayer of worship. "Liturgy is itself theological for reasons of being a meaningful understanding of such questions as why God created the destiny of anthropos, how spirit and matter interpenetrate, the cosmological presuppositions of the kingdom of God in our midst and its eschatological consequences." (David W. Fagerberg, Theologia Prima (Archdiocese of Chicago: Liturgy Training Publications, Chicago, IL, 2004), 42.)<sup>61</sup>

A statement by Kevin Irwin confirms this idea by referring to Thomas Acquinas.

<sup>&</sup>lt;sup>61</sup> Dennis C. McNulty, "The Genius of the Roman Catholic Church" (Wickliffe, Oh: Unpublished Paper, 2004), 2.

[Thomas Aquinas] asserts that the effect of the Eucharist (*res sacramenti:* literally "the thing of the sacrament) is nothing less than 'the unity of the mystical body, the church.' ...we have reiterations of what we saw in the patristic era and what is found throughout our liturgical tradition, expressed so clearly in the *lex orandi*, that Eucharist and the building up of the church are always to be seen in relation to each other. <sup>62</sup>

Irwin, quoting Rahner, indicates that the dogma of transubstantiation tells one neither more nor less than the word of Christ saying, "This is my body." Reinterpretations of the theology of Eucharist have been attempted to make it more meaningful.

[John McKenna states that,] as an explanation, transubstantiation has come under increasingly heavy fire. Some within the Roman Catholic Church maintain that this is the ("only" implied) Catholic understanding of the eucharistic presence. They stress continuity with tradition. Without this formula, they argue, the Catholic understanding cannot remain intact. They appeal to the encyclical *Mysterium Fidei* no. 24, with its emphasis on Trent. Others claim that transubstantiation once expressed a realistic understanding of the eucharistic presence but no longer does so. They seek other explanations that bring out the ecclesial dimension of this presence, that respect the communal celebration and reception of the Eucharist with its intended goals, and that take into account the mentality of modern people, for example, with a stress on personalism. They appeal to *Mysterium fidei* no. 25, with its openness to other more understandable explanations of the same reality. 64

The intellectual ontological definition of real presence is foreign to most members of the church who are not formed in a scholastic mentality. Emphasis is more on the personal encounter with Christ that takes place at liturgy, especially during communion, and not just on what is occurring in the elements during the liturgy. Schillebeeckx indicates that the desire for a reinterpretation is to safeguard the authentic doctrine but, at

<sup>&</sup>lt;sup>62</sup> Irwin, 250.

<sup>&</sup>lt;sup>63</sup> Ibid., 179.

<sup>&</sup>lt;sup>64</sup> John H. McKenna, "Eucharistic Presence: An Invitation to Dialogue," *Theological Studies*. Vol. 60, (No. 2 Pg. 7), [publication on-line] (1999, accessed March 10, 2005); available from http/library.northernlight.com; Internet.

the same time, to allow people to live the doctrine in a more authentic fashion in their existential lives. 65

There are different interpretations or meanings that people discern from the action of the Eucharist that enhance the essential meaning. Complementary approaches to the meaning of Eucharistic presence are elements of the theology of our church. Classic theology presents two such understandings of the presence of Christ in the Eucharist.

Transignification and transfinalization are two approaches that accent the action of the sacrament or what the sacrament does (res sacramenti) while not departing from the theology of transubstantiation (res et sacramentum). McKenna presents an explanation.

In offering an alternative to transubstantiation, Schillebeeckx and others have sought to preserve the traditional Roman Catholic values while bringing out values that seem to have been neglected in that framework. In effect they are trying to combine the ontological component of transubstantiation with notions such as "transfinalization" (a change in the purpose or finality of the elements and their reception) and "transignification" (a change in the meaning or sign value of these realities). 66

A further clarification from Schillebeeckx follows.

After transubstantiation has taken place, the species of bread and wine...take on a new meaning and a new finality, for they no longer remain ordinary bread and ordinary drink... they take on the new significance and this new finality because they contain a new 'reality' which we may justly term ontological.<sup>67</sup>

This is not to say that transignification and transfinalization are equal in meaning to transubstantiation. David Power indicates that Schillebeeckx did not find transignification and transfinalization an adequate substitute for the traditional language

<sup>&</sup>lt;sup>65</sup> Schillebeeckx, "Transubstantiation, Transfinalization, Transignification," 176.

<sup>66</sup> McKenna, 199.

<sup>&</sup>lt;sup>67</sup> Schillebeeckx, "Transubstantiation, Transfinalization, Transignification," 189.

about substantial change and substantial presence. Power believes that the two bring the notion of shared meaning into focus.<sup>68</sup>

Transfinalization and transignification are other ways of complementing the traditional belief in transubstantiation as the normative expression of the meaning of Eucharist. They are ways to round out the meaning of the mystery in ways that do not focus simply on the ontological change. Accented here are other nuances that assist the individual to approach the reality (meaning) as intended by Christ and understood by the church. These theologies reflect the personal encounter that allows persons with very limited cognitive abilities to be appropriate recipients. Author David Power contends that meanings such as transignification point to the meaning intended in a fuller understanding of transubstantiation.

If one is as careful as Schillebeeckx to keep the distinction between signified and signification.... Whatever communion in meaning comes about in sacrament, it does not mean the fullness of communion with the reality signified. Within the context of personal encounter, the limits of sacramental meaning are placed within the limits of present reality and at the same time are seen to express the desire for communion with Christ in eschatological fullness.<sup>69</sup>

Schillebeeckx emphasizes the personal encounter with Christ. The response of an individual is important if one is to grow in faith. However, in the church's traditions, exceptions are often made for individuals who have not reached a mature capacity to appreciate the meaning(s) of the sacrament. The baptism of infants is an example in which one who is unable to respond can be the recipient of a sacramental grace.

<sup>&</sup>lt;sup>68</sup> David N. Power, *The Eucharistic Mystery, Revitalizing the Tradition* (New York: Crossroad Publishing, 1995), 275.

<sup>&</sup>lt;sup>69</sup> Ibid., 277.

<sup>&</sup>lt;sup>70</sup> Edward Schillebeeckx, O.P, *Christ the Sacrament of the Encounter with God* (New York: Sheed and Ward Ltd. 1963).

Schillebeeckx, reflecting on St. Thomas Acquinas, highlights this tradition.

St. Thomas teaches that in children the faith of the Church makes up for the absence of their own religious intention. This means that when a sacrament is administered...to a child the communion of saints,...gathers around him in union with Christ to beg God...to bestow grace on him...This clearly brings out...the dogmatic and liturgical meaningfulness of an active and prayerful participation of the whole parish community...Unconsciousness...is no hindrance to God's merciful gift of grace.<sup>71</sup>

However, Eucharist is a sacrament that requires a response. The church's application of this requirement varies among individuals and is based on one's capacity. The preparation for communion given to a seven year old would be greatly different from the preparation given an intellectually mature adult. One is not more worthy than the other. The required understanding of the sacrament is determined by the individual's cognitive capacity. This acceptance of different capacities reinforces the ability of participation even on the part of one who cannot comprehend the meaning of real presence cognitively. The community together assists these individuals to encounter Christ in the Eucharistic Celebration. It is the totality of the communion of saints that makes this person's encounter and relationship with God grow and makes the grace a gift that has real action in the person's life. There is no concern that a sacrament can be effective despite a person's ability to perceive the total reality of the action.

The presence offered by Christ in the Eucharist naturally precedes the individual's acceptance of this presence and is not the result of it. It therefore remains an offered reality, even if I do not respond to it. My disbelief cannot nullify the reality of Christ's real offer and the reality of the Church's remaining in Christ. But ... the eucharistic real presence also includes, in its sacramentality itself, reciprocity and is therefore completely realized only when consent is given in faith to the cucharistic event.<sup>72</sup>

1010., 171

<sup>&</sup>lt;sup>71</sup> Ibid., 141.

<sup>&</sup>lt;sup>72</sup> Edward Schillebeeckx, O.P. *The Eucharist*, (New York; Sheed and Ward, 1968), 141.

The notion of the effectiveness of the Sacrament is a part of the Roman Catholic tradition. It should be considered that, in the Eastern Rite Catholic churches, the tradition of the unity of all three sacraments of initiation has been retained from the early church. In this Catholic theology, the mystery of the sacraments and supporting mystical Body of Christ are accented. Here can be found a tradition of Eucharistic participation even for those who may be unconscious to the activity or meaning.

In the Western Roman Catholic tradition, there exists the necessity of the personal response and free intention on the part of the recipient of Eucharist. A recipient must freely desire and respond to a sacrament.

The life of religion is...a free acceptance of the God who condescends to meet us... the sacrament must be a human act and...requires at least a minimum of personal involvement.<sup>73</sup>

The response is both an immediate action at the time of reception and a lived response after the celebration concludes. What would constitute a "minimal" level of personal involvement?

As noted, the church has always made exceptions for the spiritual benefit of those who do not fit the typical norms. For example, in the case of a child who is dying, Eucharist may be administered. However, even in this case, there are norms.

The Most Holy Eucharist, however, can be administered to children in danger of death if they can distinguish the body of Christ from ordinary food and receive communion reverently.<sup>74</sup>

Determining this minimum response of distinguishing "...the body of Christ from ordinary food and receive communion reverently" for persons with lower cognitive

<sup>&</sup>lt;sup>73</sup> Ibid.. 108.

<sup>&</sup>lt;sup>74</sup> Canon Law Society of America, ed., *Code of Canon Law*, "Participation in the Most Holy Eucharist," Can. 913,2 (accessed March 29, 2006); Internet.

abilities can be difficult at times. Ministers and religious educators may not be the most appropriate persons to determine the acceptable response on the part of persons with disabilities. They may need the assistance of someone who knows the person well enough to determine the intention of the recipient. This person might be a parent, a loved one, or a friend. What level of understanding is needed to encounter Christ truly? Someone who has a severe cognitive delay may never be able to express a correct definition of "transubstantiation." However, he or she often may "express," even in some non-verbal manner, the desire to receive and to participate. In this way, the person demonstrates understanding that this Eucharistic bread has a significance (transignification) that makes it different from ordinary food, that it brings the individual to Jesus, and that it makes the person part of the family or community that is celebrating God's presence in the world. This is a level of understanding that may only be perceived by someone who knows the person very well.

Barry (not his real name) is a young boy of approximately fifteen years of age.

This age is difficult to determine because of his physical disabilities. He seems to possess no motion or response to any verbal or symbolic stimuli. A wheelchair provides mobility but he cannot navigate it on his own. His parents have brought him to church regularly and would assist him by repositioning his head, at times, to observe the action. When they approached the pastor requesting that Barry be allowed to receive Eucharist there was a pastoral concern that he could not "...distinguish the body of Christ from ordinary food and receive communion reverently." The key to this person's sacramental preparation was to rely on the parents who knew Barry well enough to distinguish his responses which no one else could discern. With their help, it was realized that when

Eucharist was offered at Liturgy he would begin to move slightly and twitch his head quickly. In this movement he expressed his understanding that the Eucharist was different from ordinary food. When he did receive his First Communion, and ever since, a slight smile appeared on his face after he received. He demonstrated the understanding and reverence called for by the norms. The pastor only realized this reality due to his parents. This was Barry's response. For others, it may be a look in the eye or a gesture with the hands. Each person's response varies, as it does with all people.

In a pastoral statement for the Diocese of Chicago, Cardinal Joseph Bernardin poses an important question.

By what signs can a developmentally disabled person indicate readiness for the Eucharist? They are *desire*, *relationships* with people who share faith and prayer, and a *sense of the sacred* as manifested in behavior. Often these people cannot use words which express their understanding of the difference between ordinary bread and the Bread of God, but they can show that they recognize the difference by their manner, the expression in their eyes, their gestures, or the quality of their silence. God's desire to be in communion with the person can be presumed; the person's desire for communion must be awakened and sustained.<sup>75</sup> [Italies by author]

Is there a point where someone is so cognitively delayed that he or she should not receive the Eucharist at all? If there is absolutely no response whatsoever to the sacrament, this denial might be a consideration. The reception of Eucharist is not necessarily the only way to share in the Kingdom. There are many ways that Christ is present in our lives and that a relationship with God can be developed. Gathering with the community at liturgies, growing in relationships with others, in love shared, in the beauty of nature and the world in general, have all been vehicles by which a relationship with God can flourish.

<sup>&</sup>lt;sup>75</sup> Joseph Cardinal Bernardin, "Access to the Sacraments of Initiation and Reconciliation for Developmentally Disabled Persons" (Chicago: Liturgy Training Publications, 1985), 9.

However, Eucharist is a unique encounter with Christ that has no parallels. The uniqueness of the presence of Christ in the Eucharist makes it the paramount personal encounter within the context of the ecclesial community. Unless there is a definite reason, the individual should be given the opportunity of this unique encounter with Jesus that allows access to a grace to grow in love and faith, as he or she is able.

A minister should always err on the side of permitting the reception of Eucharist to allow the person access to God's presence in this unique way. "Cases of doubt should be resolved in favor of the right of the baptized person to receive the sacrament. The existence of a disability is not considered in and of itself as disqualifying a person from receiving the Eucharist."

In the end, one of the ultimate purposes of the Eucharist is not about Eucharistic action itself but about the entire Christian life itself. In the end, one of the ultimate purposes of the Eucharist is not to get the ritual right, but to get *life* right. Or—at least until the kingdom comes—to get life less wrong.<sup>77</sup>

#### Canonical Rights to Eucharist

The Sacraments are essential to the building up of the Body of Christ. In themselves, they hold an importance because "the sacraments of the New Testament were instituted by Christ the Lord and entrusted to the Church." They are a direct connection to the life in God through Christ in the power of the Holy Spirit. More than this, the sacraments belong to the church. Through their baptism, persons with disabilities also belong to the church. Peter Vere states that this is reason enough to "ensure their

National Conference of Catholic Bishops, "Guidelines for Celebration of the Sacraments with Persons with Disabilities" (Washington: National Catholic Office for Persons with Disabilities, 1995), 9-10.

<sup>&</sup>lt;sup>77</sup> Irwin, 330.

<sup>&</sup>lt;sup>78</sup> Canon Law Society of America, ed., *Code of Canon Law*, "The Sacraments," Can. 840 (accessed March 29, 2006).

[persons with disabilities] full-participation in the Church's liturgical life...the availability of extraordinary means [through which we come to Christ] is no reason to cut off the mentally and the cognitively challenged from the ordinary means through which Christ draws his faithful closer to him."<sup>79</sup> All members of the church community are called to share in this life through the Sacraments as one is called.

As actions of Christ and the Church, they [the Sacraments] are signs and means which express and strengthen the faith, render worship to God, and effect the sanctification of humanity and thus contribute in the greatest way to establish, strengthen, and manifest ecclesiastical communion. Accordingly, in the celebration of the sacraments the sacred ministers and the other members of the Christian faithful must use the greatest veneration and necessary diligence. 80

When ministers make decisions as to the appropriateness of a sacrament for a person with disabilities, they usually believe that they are following the current Canon Law of the Roman Catholic Church.

[Peter Vere and Ian Bergess state that] Too often, when carrying out the Church's public ministry, our local Catholic communities neglect the rights of those mentally and developmentally challenged. This happens, unfortunately, despite canon 213's following admonition: "Christ's faithful have the right to be assisted by their Pastors from the spiritual riches of the Church, especially by the word of God and the sacraments." In short, like all other Catholics, the mentally and developmentally challenged possess the canonical right to be assisted by the Church through catechesis and the administration of the sacraments. <sup>81</sup>

Unfortunately, decisions concerning the administration of the sacraments are often based on erroneous or limited interpretation of Canon Law. Canonist John Huels points out the difficulty in interpreting Canon Law. He emphasizes that trained canonist

<sup>&</sup>lt;sup>79</sup> Peter J. Vere, J.C.L. "Calling God's Special Children to Holiness: Sacramental Access for the Mentally and Cognitively Challenged," *Proceedings of the Sixty-Sixth Annual Convention* (Canon Law Society of America, 2005), 199.

Society of America, ed., Code of Canon Law, "The Sacraments," Can. 840 (accessed March 29, 2006); Internet.

<sup>&</sup>lt;sup>81</sup> Peter Vere and Ian Bergess, "The Canonical Rights of God's Special Children," *Homiletic and Pastoral Review* 103 (7): 61-62, 64-66 (2003), 61.

should be the source for appropriate interpretations.

Canon Law, like civil law, is a complex system which requires trained experts to interpret it properly. ... The best interpretation of a Church law is not always evident from an initial reading of it. For example, when a canon requires the 'use of reason' for the reception of first Holy Communion, what does this mean? Does it even apply to persons with developmental disabilities? If so, does it mean that mentally retarded persons and others with kindred developmental disabilities are excluded permanently from that sacrament?<sup>82</sup>

As far as general principles for all of the sacraments, the United States

Conference of Catholic Bishops has clearly enunciated the general principles that apply to
persons with disabilities.

By reason of their baptism, all Catholics are equal in dignity in the sight of God, and have the same divine calling. Catholics have a right to participate in the sacraments as I'ull functioning members of the local ecclesial community (can. 213). Ministers are not to refuse the sacraments to those who ask for them at appropriate times, who are properly disposed, and who are not prohibited by law from receiving them (can. 843, 1). Parish sacramental celebrations should be accessible to persons with disabilities and open to their full, active and conscious participation, according to their capacity. 83

In regards to the Eucharist, Canon Law states that, "Any baptized person not prohibited by law can and must be admitted to Holy Communion". It does not stop here. There are requirements for the recipient. Canon Law continues by saying that,

The administration of the Most Holy Eucharist to children requires that they have sufficient knowledge and careful preparation so that they understand the mystery of Christ according to their capacity and are able to receive the body of Christ with faith and devotion. 85

<sup>&</sup>lt;sup>82</sup> Huels, John M., O.S.M., "Canonical Rights to the Sacraments," *Developmental Disabilities and Sacramental Access*, Edward Foley, ed. (Collegeville, Minnesota: The Liturgical Press, 1994), 94.

<sup>&</sup>lt;sup>83</sup> National Conference of Catholic Bishops, "Guidelines for Celebration of the Sacraments with Persons with Disabilities," 2, 4.

<sup>&</sup>lt;sup>84</sup> Canon Law Society of America, ed., *Code of Canon Law*, "Participation in the Most Holy Eucharist," Can. 912 (accessed March 29, 2006); Internet.

<sup>85</sup> Ibid., Can. 840 (accessed March 29, 2006); Internet.

"Capacity" is an interesting concept when it is applied to persons with cognitive disabilities. The sacraments are not just about an intellectual understanding. They are a living reality into which we grow in our understanding and faith. The Rite of Christian Initiation for Adults (RCIA) in the Roman Catholic Church emphasizes *mystagogia* which is similar to the eastern approach of being initiated first and then growing in one's faith. "*Mystagogia* is a Greek word for 'understanding of the mysteries,' which are primarily the sacraments... *mystagogia* is also understood as ongoing faith formation. It is the continuous process whereby one deepens one's faith through Biblical studies, deeper catechism class or other forms of adult education."

Children also participate in the RCIA but in a separate process designed for them.

The RCIA clearly understands that the cognitive capacity of children is different from that of adults. The expectations are designed for the child's mind. The same model can be used to provide a RCIA program for children or adults with low cognitive abilities.

Darren, the adult with cognitive disabilities mentioned previously. participated in such a program. The Parish of St. Augustine in Cleveland, Ohio has developed an RCIA program for persons with various disabilities. As appropriate, they participate along with the typical parish members. Children with more severe cognitive disabilities participate in "The Beatitudes Program," an RCIA opportunity designed for them. Assisting the individual in the formation of faith is at the heart of *mystagogia*.

The sacraments are for the community and for the building up of the Kingdom.

The sacraments of initiation are the beginning steps in the life of faith. The Eucharist is

<sup>&</sup>lt;sup>86</sup> St. Bernadette Parish Website, 7600 S. 42nd St. Bellevue, NE 68147 [website on-line] (N.D., accessed September 4, 2006); available from http://www.stbernadetteparish.org/sbc/faithformation.html; Internet.

one of the three sacraments of initiation: Baptism, Confirmation and Eucharist. To understand the right to Eucharist we must see it as the "summit" of the initiation process into full membership in the church.

The Eucharist is the most august sacrament, in which Christ himself is contained, offered, and received, and by which the Church constantly lives and grows. It is the summit and source of all Christian worship and life, signifying and effecting the unity of the people of God, providing spiritual nourishment for the recipient, and achieving the building up of the Body of Christ. The celebration of the Eucharist is the center of the entire Christian Life. <sup>87</sup>

As the sacrament that signifies the "unity of the people of God" and the essential way of "building up the Body of Christ," there is a great obligation to include all who are members of the Body of Christ on earth. As we expand our understanding of God's calling forth of all people into the Kingdom of God, there should be special attention given to those who are marginalized. The church's social justice principles are built on sacramental theology and the calling of all people to the table.

Preparation for the reception of the Eucharist is an important obligation of both the parents and the pastor.

It is primarily the duty of parents and those who take the place of parents, as well as the duty of pastors, to take care that children who have reached the use of reason are prepared properly and, after they have made sacramental confession, are refreshed with this divine food as soon as possible. It is for the pastor to exercise vigilance so that children who have not attained the use of reason or whom he judges are not sufficiently disposed do not approach holy communion. <sup>88</sup>

Pastors, at times, have been over diligent in this duty by expecting persons with cognitive disabilities to follow norms too strictly. In our efforts to treat all persons in the

<sup>&</sup>lt;sup>87</sup> Canon Law Society of America, ed., *Code of Canon Law*, "The Most Holy Eucharist," Can. 897 (accessed March 29, 2006); Internet.

<sup>88</sup> Ibid., "Participation in the Most Holy Eucharist," Can. 914 (accessed March 29, 2006); Internet.

same way, it is important not to overlook and to understand the differences that make each person unique.

Scripture teaches us that "any other commandment there may be [is] all summed up in this: 'You shall love your neighbor as yourself.'"(Rom.13:9) In His wisdom, Jesus said, "as yourself." We must love others from the inside out, so to speak, accepting their difference from us in the same way that we accept our difference from them.<sup>89</sup>

Over diligence in sacramental preparation can be the cause of the person not being allowed to receive the sacrament based on a perceived lack of sufficient preparation in comparison to typical peers.

The canon contains laws that are both changeable and others that are unchangeable. The laws that refer to divinely-given structures, such as the sacraments, are unchangeable. Others that refer to the order or discipline of church life, such as the rules that govern age of reception of the sacraments or the process of preparation to receive a sacrament, are changeable. These ecclesiastical laws reflect current understanding of God and God's action in our lives. Earlier in church history, Eucharistic practices followed different norms. According to Huels, "For the first twelve hundred years of Christian history infants received Communion in the Western Church." One response might be to call for the initiation rites to include all three sacraments. Full initiation would recognize the person's full personhood and would allow a greater emphasis on *mystagogia*.

However, current Roman Catholic Church's practice does treat persons with developmental disabilities as an exception to the law. Cardinal John Wright, as prefect of the Congregation for the Clergy wrote:

<sup>&</sup>lt;sup>89</sup> United States Conference of Catholic Bishops, *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities*, Article 3.

<sup>&</sup>lt;sup>90</sup> Huels, 104.

As far as the profoundly handicapped are concerned there is no doubt that they belong to a special portion of the People of God, and they do need special attention on the part of parents and educators, who should ultimately decide whether the children are ready to approach the sacraments or not. 91

Flexibility can be seen in the *Directory for Masses with Children*. Those who have mental or physical disabilities are not directly treated "because a broader adaptation is sometimes necessary for them." The norms should be applied "with the necessary changes." In pastoral situations, Canon 914 has presented the greatest dilemma in allowing persons with severe disabilities to receive Eucharist.

This admonition is that pastors should be watchful that no one receives the sacrament who has not reached the age of reason or who is not sufficiently disposed. On this point the National Conference of Catholic Bishops made an important comment.

It is important to note, however, that the criterion for reception of Holy Communion is the same for persons with developmental disabilities and mental retardation as for all persons, namely, that the person be able to *distinguish the Body of Christ from ordinary food*, even if this recognition is evidenced through manner, gesture, or reverential silence rather than verbally. Pastors are encouraged to consult with parents, those who take the place of parents, diocesan personnel involved with disability issues, psychologists, religious educators, and other experts in making their judgment. If it is determined that a parishioner who is disabled is not ready to receive the sacrament, great care should be taken in explaining the reason for this decision. *Cases of doubt should be resolved in favor of the baptized person to receive the sacrament*. The existence of a disability is not considered in and of itself as disqualifying from receiving the Eucharist. <sup>93</sup> [Italies by author]

A pastor should resolve the doubt in favor of the baptized person by allowing the person to receive the Eucharist. God desires a personal relationship with the individual

<sup>91</sup> Huels, quoting John Cardinal Wright's Letter, 23 November 1978. (Prot. 159082/11), 105.

<sup>&</sup>lt;sup>92</sup> Congregation for Sacraments and Divine Worship, *Directory for Masses with Children* [Published on-line] (1973, accessed March 16, 2007); Available from http://www.adoremus.org/DMC-73.html#anchor4421011; Internet.

<sup>&</sup>lt;sup>93</sup> National Conference of Catholic Bishops, "Guidelines for Celebration of the Sacraments with Persons with Disabilities," 9-10.

within the context of the church community. God will take action to develop this relationship despite a person's abilities. Religious leaders can assist in the development of this relationship. As a fundamental step to assist God's desire, "parish sacramental celebrations should be accessible to persons with disabilities and open to their full, active and conscious participation, according to their capacity."

Canon Law states that it is the pastor's obligation to allow for catechetical formation for persons with disabilities. Canon 773 begins by stating that catechesis of the faithful is the obligation of pastors.

It is a proper and grave duty especially of pastors of souls to take care of the catechesis of the Christian people so that the living faith of the faithful becomes manifest and active through doctrinal instruction and the experience of Christian life. 95

Then the code continues dealing with specific groups within the parish community that should be given particular attention. Canon 777, 4 states that the pastor, in accord with norms established by the diocesan bishop, is to ensure "that catechetical instruction is given also to those who are physically or mentally impeded, insofar as their condition permits." This canon requires pastors to provide religious education for persons with disabilities.

The pastoral dilemma of how to adapt the education to the needs of the individual is often a major obstacle for the integration of persons with disabilities into the life of the church. The reality is that almost every person with a developmental disability, no matter how severe his or her condition, can respond when the proper catechetical methodologies

<sup>&</sup>lt;sup>94</sup> Ibid., 4.

<sup>&</sup>lt;sup>95</sup> Canon Law Society of America, ed., *Code of Canon Law*, "Catechetical Instruction," Can. 773 (accessed March 29, 2006); Internet.

<sup>&</sup>lt;sup>96</sup> Ibid., Can. 777, 4 (accessed March 29, 2006); Internet.

are employed.

Quoting advice given by Rev. Thomas Cassidy, professor of Canon Law at Saint Paul University, Peter Vere states, "Canon Law is clear. The mentally and cognitively challenged have a right to receive the sacraments." This is the major conclusion of this section. Overly rigid application of the law destroys the intent of the law. The canonical principle of *favors are to be multiplied, and burdens restricted* serves as a *modus operandi* in sacramental participation for persons with disabilities.

## Section 3: Suggestions for Pastoral Practices/ Pastoral Statements/Pastoral resources

It is nearly impossible to detail every possible pastoral practice that might be used to welcome persons with disabilities and their families into the church community. There are physical modifications that can be made in order to make a building "welcoming," and our parishes should strive to do this as possible. More importantly, there is need for an attitudinal modification, a catharsis, on the part of the pastor, priests, parish ministers and the congregation (and in that order) to achieve true integration of persons with disabilities into the life of the parish. Much in this paper serves this pastoral perspective. There are useful materials that can assist overcoming physical and attitudinal barriers. A few general principles are important considerations to for reflection.

Disabilities are unique and personal to that individual. As such, each person with a disability should be given the same dignity every person deserves, to be seen as an individual with talents and needs that are different yet similar to all people. This notion is supported by the United States Conference of Catholic Bishops.

<sup>&</sup>lt;sup>97</sup> Peter J. Vere, J.C.L. "Calling God's Special Children to Holiness: Sacramental Access for the Mentally and Cognitively Challenged," 195.

What individuals with disabilities need...is acceptance in this difference that can neither be denied nor overlooked. No acts of charity or justice can be of lasting value unless our actions are informed by a sincere understanding love that penetrates the wall of strangeness and affirms the common humanity underlying all distinction.<sup>98</sup>

The author suggests that, instead of waiting for persons with a disability to approach the church, the church should actively seek them out. In many cases, they and their families are the ones who already feel rejected and isolated. It is the task of the church to look for families with a member who has a disability, to show concern that everything possible is being done to help them to participate in parish life. Until they are comfortable, individuals should be visited regularly by the parish ministers or volunteers. Parish issues dealing with disabilities can easily become part of the social justice agenda of a parish council.

A good beginning in reaching out to families or individuals not ready to join the active church community is to assist them in getting in touch with organizations that might help them. The person should never be just "handed over" to an organization. Personal involvement is very important. Parish members can find ministry in being a voice for those who cannot speak for themselves. When persons with disabilities have begun to be involved in parish life, another parish ministry can be created to assist an individual, as needed, in being introduced to members of the community and to assist the person in exploring their options for participation.

The parish needs to become the learner and not the expert. There is a tendency to view the individual and his or her needs according to a definition of the disability.

Definitions are not an accurate representation of the person. They serve only as a way for

<sup>&</sup>lt;sup>98</sup> United States Conference of Catholic Bishops, *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities*, Article 3.

society to categorize persons according to some standard. Typically, definitions might be valuable only in accessing services in the community. Definitions can change for different age groups. They are incomplete in a pastoral setting. An example of this issue might be one in which a person who is assigned twelve individuals with autism for religious instruction. Understanding the definition might assist the instructor initially, but the spiritual needs and abilities of the twelve will be different. One must treat the person as an individual, and one must learn his or her needs and abilities. Anyone who initially approaches a person with a disability should allow that person to instruct the minister or parishioner on what assistance is needed. This approach allows the person to grow as an individual and not as a definition. In addition, this tactic gives a sense of pride and control over one's life and the choices one makes.

In the area of Eucharistic reception (as well as the other sacraments) ministers should rely on the desire for a relationship, an encounter, with Christ. The concern should not just because the person with a disability may have difficulties or limitations. Sacramental participation is also a matter of "building up the Body of Christ."

By welcoming developmentally disabled people through the waters of Baptism, the oil of anointing in Confirmation, the consecrated bread and wine of the Eucharist and the peace and joy of reconciliation, the parish builds up the Body of Christ.

From our parents and grandparents we have received the rites by which we give thanks, intercede, anoint and confirm, marry and bury. We do them over and over, and we teach our children to do them. Thus do we discover what it is to be a Christian and a Catholic. We learn this in hearing the Word of God, in the hymns and acclamations, in the genuflections and the kneeling, in the greeting of peace, in sharing the consecrated bread and wine at the holy table. *The liturgy is not an 'extra,' something nice that may give us good feelings. It is our life, our very spirit. It is the source of our identity and renewal as a Church.'* (Our Communion, Our Peace. Our Promise, pastoral letter on the liturgy by Joseph Cardinal Bernardin, Chicago, 1984). [Italics by author]

<sup>&</sup>lt;sup>99</sup> Bernardin. 10.

#### The Call to Integration

From what has been stated from the theology of the dignity of the human person, the ecclesiological call of the church, as well as the canonical and sacramental aspects of church teachings, it is clear that persons with disabilities are equally called to participate in all aspects of church life according to their abilities and their personal vocations as disciples in the community. Baptism guarantees them a place. The sacraments assist them in their developing relationship with God. Church life allows them to participate in the community that is creating and still moving toward the full Kingdom of God. It is the church's recognition of their call as disciples that enable the church to evolve a fuller understanding of the personhood and the diversity that makes up this Kingdom.

#### **Evangelization**

Everything that has been stated here has been stated in church documents, books, and other media. The original United States Conference of Catholic Bishops' Statement in 1978 expressed much of the theology contained in this paper. If one were to search the Vatican on-line library for the word "disabilities." twenty-two separate papal statements would become available. The theological and the theoretical foundations are present and have been promulgated since the carly 1970's. The audience that needs to be reached with this "good news" is often missed.

There is a need to further evangelize persons with disabilitics. Our church has attempted this evangelization in many traditional ways, but there is a vehicle that has virtually been untapped. The internet has become a powerful "community gathering spot" where people are shopping and searching for information.

Ray Hurst, researcher of internet usage, states that, "at the end of 1998 there were between 60 and 160 million users worldwide, give or take a few million and depending on who you believed." 100

Current global estimates (2004-5) indicate that there are upwards of 700 million of us online, 840 million according to the Globalreach Research Agency. According to research company Nielsen there are upwards of 34 million Britons currently connected. And, as of December 2004, there were some 190 million Europeans online says stats compiler Nua, who also break global usage down country by country. It's an inexact science and these figures are best guesstimates, but there's no question which way the graph's moving. Predictions for 2005 suggest getting on for a billion people online globally, with Europe and Asia-Pacific growing faster than the U.S.<sup>101</sup>

According to Globalreach Research Agency, 194 million English speaking Americans currently use the internet. This figure does not include the non-English speaking Americans. The point is that, if the internet is where people are accessing information, then this is where the church needs to evangelize. It provides one more opportunity to evangelize persons with disabilities and those who care for them.

The theological and theoretical foundations for the integration and for the calling forth of persons with disabilities into full discipleship are clearly evident in the church's teaching. Making the church accessible is a duty to bring all people into the Kingdom. It is more that a duty. It is a labor of love. For to further God's Kingdom and to enrich our church with an ever-more diverse community of disciples is our calling, our way to express God's love for all people. Pope John Paul II expressed eloquently that life is

<sup>&</sup>lt;sup>100</sup> Ray Hurst. "How Big is It? 2006," [article on-line] (2006, accessed April 18, 2006); Available from http://www.bcentral.co.uk/marketing/ebusiness/how-many-people-use-the-internet-what-do-they-use-it-for.mspx; Internet.

<sup>101</sup> Ibid.

<sup>&</sup>lt;sup>102</sup> GlobalReach research agency [article on-line] (2004, accessed April 18, 2006); Available from http://global-reach.biz/globstats/details.html; Internet.

measured by love and not by disability.

How eloquent are your words for us today, Lord of life and hope! Every human limitation is ransomed and redeemed in you. Thanks to you, disability is not the last word on life. *Love is the last word*; it is your love that gives meaning to life. <sup>103</sup>

The thesis of Chapter 2 is that persons with disabilities have a right, as all members, to full participation in the church. In order to arrive at this conclusion, the case for the full integration of persons with disabilities was considered from two approaches. The first considered the church's call to integration by considering the call to promote social justice by action. Next, its ecclesiology calls the church to stand as servants to the marginalized. Considering persons with disabilities as marginalized individuals was developed by examining their history of oppression since mid-1800 and by considering statistics that demonstrate their current social position.

Most fundamentally, the basis for an individual's right to full membership in the church is based on their call from God to join the community of disciples. Their full personhood in the image of God calls the church to recognize that which already exists. Persons with disabilities bring talents and a different perspective to the church and its mission. The evolving Kingdom is incomplete without them.

This project calls for the consideration of a new methodology to evangelize and to assist persons with disabilities to be further integrated into the church community. The actual project is the creation of a website dedicated to presentation of church teachings and practical suggestions to promote the integration of persons with disabilities. Will a

los John Paul II. "Jubilee of the Disabled, Homily of John Paul II." Sunday, 3 December 2000 [homily on-line] (Vatican on-line library, 2000, accessed April 18, 2006); Available from http://www.vatican.va/holy\_father/john\_paul\_ii/homilies/2000/documents/hf\_jpii hom 20001203 jubildisabled en.html; Internet.

website of this nature be helpful? Will people find information that conveys the teachings of the church or pastoral suggestions to assist a person with disabilities? What suggestions might assist them? Chapter 3 presents a narrative of the methodologies employed to answer these questions. It describes an overview of the building of the website and the process of assembling a survey team to assess its value. It is hoped that the project will determine the value of this new medium to convey the message of the person's call to join the community of disciples.

#### CHAPTER 3

#### PROJECT METHODOLOGY

Chapter 2 presented several theological and theoretical perspectives for the integration of persons with disabilities into the life of the church. This chapter presents an overview of some of the project methodologies for building and maintaining a unique website. The site promoted the teachings and theories discussed in Chapter 2 and also suggested practical ways to integrate persons with disabilities into the community of the church. The uniqueness of the project is the utilization of a new format. As this chapter discusses, it appears that the internet has never been used for this purpose. This project tested the hypothesis that an internet website could provide a valuable new arena for ministry. The objective of this project would be to create a user-liriendly website to assist priests, parish ministers, teachers, family members, and, especially, persons with disabilities to access Catholic teachings and pastoral suggestions. The intent was to assist persons with disabilities to participate as I'ully as possible in church life. Chapter 4 presents statistics and suggestions from the survey team that point to the success or failure of the project. This chapter deals with the mechanics, the how of building the website.

The methodologics presented in this chapter are not sequential, for many steps took place concurrently. This chapter highlights only the key items employed in the construction of this particular website. However, many of these points can be used to build any interactive website.

#### Revisiting the Mission

Throughout the construction and revision of a website, it is important to return periodically to the mission, the goals or the purpose of the site. Prior to the initial stages of the work, the overall goal of the site had been determined to be the creation of a user-friendly venue to assist priests, parish ministers, teachers, family members, and, especially, persons with disabilities to access Catholic teachings and pastoral suggestions. The hope was that these teachings and suggestions would assist the person with a disability to participate more fully in church life. Because it is important to the project, the author reiterates the mission several times throughout these pages. It is important to keep the mission in the forefront of one's strategy and tactics. As a result, four measurements of success were formulated. These outcomes would assist in judging success or failure. The project would have been considered a success if it:

- 1. Determined the participants' level of understanding of church teachings and pastoral practices in the area of ministry to persons with disabilities.
- 2. Determined the type of information that a theological and pastoral website should provide.
- 3. Provided information that would assist persons with disabilities, families, priests and pastoral ministers, etc. to further enhance an understanding of the church's acceptance of persons with disabilities into the life of the church.
- 4. Provided an interactive medium that could adapt to new questions and needs.

#### Determining the Target Group

Determining which people might benefit from the website was fairly easy. The target group flowed from the mission statement. "Priests, parish ministers, teachers, family members, and, especially, persons with disabilities" were identified in the early stages as those whom the website might attract. The site must benefit each. However, each of the groups has different interests and different levels of access to the internet.

Current statistics indicate that the use of computer technology by persons with disabilities is less than that of those without disabilities. Considering the statistics, the author anticipated that the initial visitors might not be persons with disabilities as much as those who minister to or care for them. On the other hand, considering the increase in internet use, previously described, the website was constructed with a mindset in which many more people would use the internet, including more persons with disabilities. Therefore, the author created the website for all members of the target group. At the start, the site was to provide general teachings and suggestions that could be used by all groups. The visitors would suggest further revisions or additions. The hope was that, as the use of the internet increases, a more diverse group will participate. The website can be flexible to expand in new directions. Flexibility is one of the unique features of this medium. When considering a target group, it is important to think of both the present and the future.

## Determining the Originality of the Project

The project began in October 2004 and was completed in October 2006. There were several questions that had to be addressed before beginning. Did such a website already exist? If one did, then the project might have been redundant or not needed because it would not have added anything to the field of ministries to persons with disabilities. The project, of course, could have been confined to the Catholic Diocese of Cleveland, and simply link to preexisting information. The other question was, if a website did not exist, why not? Had others already determined that it was not needed?

<sup>&</sup>lt;sup>104</sup> George W. Bush, The *New Freedom Initiative*. See Appendix B for statistics on the computer use of persons with disabilities.

<sup>105</sup> The initial visitors to the website were not representative of all desired target groups. As a result, the initial version of the site was overly representative of the needs of specific groups, especially parents of persons with disabilities. The author believes that this trend will eventually change as persons with disabilities visit the site.

After answering these questions, one could then determine whether or not the site would be useful to the target groups.

In October 2004 the author contacted the executive directors of the following national organizations: The National Catholic Partnership with Persons with Disabilities, the National Catholic Office for the Deaf, the National Catholic Office on Inclusion Ministry, the National Office on Disabilities and the University of Dayton. <sup>106</sup>

After a brief explanation of the doctoral project, each director was asked two questions, "Do you know of any such websites?" and "Do you think this (planned site) would be a useful website?"

Each organization responded that no such website, to their knowledge, existed. Some suggested other internet sources of information. The majority of these sources were websites concerned with the ministry to persons with disabilities. The author visited each of these websites. Then he sent each of these organizations the same two questions. Finally the conclusion was that no such website existed that would offer both Catholic teachings and practical, pastoral suggestions. The author's challenge was to create a prototype that might serve as a model. The ideal model would be one that could easily be applied and implemented for other such projects.

## Determining the Need

When inquiring if such a website existed, the author also asked the national organizations if there was a need for such a website and if it had a value or could make a difference. The responses were unanimous and enthusiastic. Without exception, each organization stated that the website was needed and could create a "presence of hope" on

<sup>&</sup>lt;sup>106</sup> The University of Dayton has a large field of study in the area of disability ministry

the internet. Each respondent believed that the value of the website would be to increase the presence of the church to persons with disabilities. Charleen Iannucci wrote that "Your plans for a website are timely and welcomed. Everything we do helps implement the U.S. Bishops' Pastoral Statement and Sacramental Guidelines for this ministry." Janice L. Benton responded "...it would be a great service for all of us... There is definitely a need for practical and specific information. I think a good website is the best way to share such information." <sup>108</sup>

The obvious question then became why has no one created such a website? The response from the organizations, again, was unanimous. It came down to the issues of time and money. Several respondents stated that they would like to see such a website, but because of their budgetary constraints, they did not have the capacity to undertake such an effort. A few mentioned that there was also the issue of a lack of theological and pastoral expertise. They stated that they knew of no one with the credentials to provide the needed foundation. These responses answered the question from a national perspective. However, the question remained, would the website seem to be a value to the people it wished to attract?

To answer this question, the author surveyed ten priests, two religious sisters, and five parents of children with disabilities. The survey was conducted either by phone or in person. The author asked the same question posed to national organizations, "Would the website have a value or make a difference?" Each voiced a unanimous consensus that the website would have a value to the target groups. It is also interesting to note that each

<sup>&</sup>lt;sup>107</sup> Charleen Iannucci, Department of Ministry with Persons with Disabilities, Archdiocese of Galveston-Houston. Email correspondence, October, 2004.

<sup>&</sup>lt;sup>108</sup> Janice L. Benton, Executive Director of the National Catholic Partnership on Disability. Washington, DC. Email correspondence, October, 2004.

voluntarily added that they each saw the site as a "website for them," something that would give them a place to find information about their pastoral concerns in ministering to persons with disabilities. From this informal survey, the author determined that there was sufficient evidence that the website would be a value, and the project should proceed. The next major consideration was to determine the cost of the project.

#### **Determining the Cost**

It was important to determine at the beginning of the project if a cost effective website could be created. Websites can be created for almost little or no cost or they can cost thousands of dollars. What would make the difference? Factors included:

- How large of a site it is going to be?
- How much memory will it need?
- How many people a month will visit?
- What the site will do? Will it simply present information? (This would require a small amount of memory)
  - o Will the site be highly interactive?
  - Will it allow for discussion sections or advanced search functions such as found on the <u>Google</u><sup>©109</sup> Site?
  - Would the site be created and maintained by a company or by oneself?
     (The costliest consideration)

Regarding these issues, the author consulted with several owners of companies that create and manage websites. In addition, Ralph Joyce, Webmaster of Information Services (IS), Catholic Charities Health and Human Services, was a valuable source of information. An initial estimation was that the total cost of the proposed website project,

<sup>&</sup>lt;sup>109</sup> Google<sup>©</sup> is the most popular internet search engine in America at the present time. ©2006. Information is available from http://www.google.com.

<sup>&</sup>lt;sup>110</sup> Catholic Charities Health and Human Services of the Cleveland Diocese will be referred to and will play an important role in this project. Throughout these pages the Catholic Diocese of Cleveland, Ohio will also received particular attention. See footnote number 2 for more information.

including the construction of the website, ongoing maintenance of the site, mailings, and other miscellaneous items could cost between \$5,000 and \$15,000. Most of this money would pay for the initial construction.

As it turned out, the project would have been much more expensive if a company had constructed it. In October 2006, the author asked other expert individuals what a website like *Catholicdisabilityteachings.com* would have cost just to build. After reviewing the site, Julie Yack, Chief Operating Officer for Colorado Technology Consultants, Inc. estimated that the website, as it had been constructed, would have cost between \$7,500 and \$15,000 if a company had been hired. That figure would only cover the initial creation of the website. The ongoing hosting and upgrades, depending on the cost of each upgrade, would cost some \$1,200 per year. This amount would be needed to continue to maintain and update the site. In addition, any programming work would cost approximately \$150 per hour. At the beginning of a project such as this, it is important to evaluate the overall cost carefully. The question became: how does someone reduce the overhead?

Considering the large initial cost estimate for the project, the author had to reach a decision. Either he could either find someone to volunteer to build the website, or he would have to learn to create the site by himself. A few attempts were made to find a company that might donate expertise. This effort was abandoned when no company replied. There was a new hope when a university professor took an interest in the project and agreed to make the creation of the website a class project for the fall semester.

Julie Yack, Chief Operating Officer, Email Correspondence, October 2, 2006. Colorado Technology Consultants, Inc. 2928 Straus Lane Ste 200 Colorado Springs, CO 80907.

Unfortunately, during the spring, funding was cut and the professor was forced to resign in order take a position at another university in California, ending this possible website creation source.

In October 2004, the author decided to create and maintain the website himself. This decision necessitated attending classes and participating in online tutorials to develop the necessary skills. The program selected to create and manage the site was <a href="Frontpage 2003">Frontpage 2003</a>. The initial cost to purchase the program was \$100. There are several other equally effective programs, but <a href="Frontpage 2003">Frontpage 2003</a> was chosen because it is used to create and maintain all Catholic Charities websites. Developing the skills in this website program would allow for the editing and management of other existing sites.

There is a negative side to this decision. Independent maintenance of the website increased the pressure and the work involved in the overall project. Nevertheless, the savings were substantial. The other benefit was that, once created, there would be greater control of the site, which allowed for greater interactive communication with the visitors to the site. The decision would allow for updates to the site to be handled quickly. The elimination of a managing company cut out a middle step and increased efficiency.

Created in this manner, the website would have a yearly cost of approximately \$155, including the cost for "renting" the space for the website and the cost for use of the domain name. The positive aspects certainly outweighed the negative.

#### Funding the Project

Funding a project like this is possible. There are grantors that offer one-time funds to underwrite the creation of a website for the benefit of a specialized population.

 $<sup>^{112}</sup>$  Frontpage 2003, Microsoft Corporation.  $^{\$}$  2006. Information is available from http://office.microsoft.com/en-us/FX010858021033.aspx.

However, there were two drawbacks in this particular instance. First, the site is geared to primarily a Catholic audience. Most foundations will not finance projects that have a specific target group based on religion. Second, and more important, this project was not created under the auspices of a Federal Code 501(C) 3, a "not for profit" entity. Foundations will only provide funding to an organization that is a 501 (C) 3.

By chance, a small family-owned foundation understood and appreciated the vision of the project. The owners of the fund were willing to finance the project, not through the foundation, but through a personal donation. A project like this must be created through personal donations or be connected to a 501 (C) 3 organization.

### Creating a Project Chart

One of the most important steps was the creation of a project chart. The chart would outlined on a graph the estimated completion dates for every aspect of the project. This effort would give a rough guess at the due dates for each goal. As time went on, the chart was revisited and the timeline was reconfigured. The key to the chart is to employ flexibility. Most of the items listed below were initially seen as part of the project chart. However, the author treats items of importance that were not envisioned at the beginning of the project and so are not reflected in the chart. 114

# Forming a Focus Group

On November 1, 2005 the author invited ten individuals to be members of the focus group. The aim was to choose people who reflected the target population. The first ten people contacted accepted the invitation. Each showed great interest in the project, as

<sup>113</sup> The directors of this foundation wish to remain anonymous.

<sup>114</sup> See Appendix D.1 for a sample of the proposed project timeline.

evidenced from their enthusiastic responses. One person said that she did not want to miss this opportunity. Each member saw the invitation as the chance to help create something that did not exist, and to be present at the dawn of a new area of ministry.

The members were comprised of:

- Two Roman Catholic priests. Both are leaders in providing ministries for the Deaf and persons with cognitive disabilities. In addition, one has wide experience in ministering to the Blind and persons with mental illnesses.
- Two Roman Catholic religious sisters. One possesses a master's degree in special education and is active in ministries to the Deaf. The other is a member of the Catholic Commission on Social Justice of Catholic Charities Health & Human Services.
- Three laywomen. One described herself as "being around persons with cognitive disabilities since she was six years old." She has made her career as the implementer of innovative programs for two of Ohio's County Boards of Mental Retardation and Developmental Disabilities. The second woman is a person who uses a wheelchair due to cerebral palsy (CP). Despite her challenges, she serves her parish as the director of religious education for children with cognitive and other developmental disabilities. The third woman is Hispanic and a member of the Catholic Deaf community. She serves the federal government by directing special projects and in-services at the Federal Building in Cleveland, Ohio. This role allows her to advocate for persons with disabilities on a daily basis.
- Three laymen. One is the news director for a local television station. He is a strong advocate for persons with cognitive and other developmental disabilities. In his career he has produced many news segments, special videos and short documentaries on this group. He is the brother of an adult with cognitive disabilities. The second man has a strong background in mental health services and designs new programs for Catholic Charities Health and Human Services. He has a daughter who is hearing impaired. The third man has worked for fifteen years providing programs for persons with cognitive disabilities. He currently directs a family center in the city of Lorain for Catholic Charities Health & Human Services serving a wide array of populations, including persons with disabilities. 115

As the meeting progressed, two members were added. Initially the author invited a sign language interpreter as a paid professional. She became drawn into the meetings and became an active participant. Lastly, a seminarian from the St. Mary Seminary and Graduate School of Theology attended the meetings after the first session. He had been

<sup>115</sup> See Appendix E for a list of names and titles of the members of the focus group.

assigned to St. Augustine Church, home of the Cleveland Catholic Deaf Community, and was interested in this project. In addition, his pastor felt that this would be a good experience. Most of the members were strong advocates for some area of social justice. A few felt embarrassed to be present, stating that they felt inferior to the other members. At the first meeting, after a short time of allowing each person equal freedom to speak, members of the group became comfortable with each other and with their own roles in the focus group.

The first mccting was held February 2, 2006. The procedure of orchestrating and conducting this session demonstrated a solid methodology for how to carry out meetings that included individuals who are deaf and/or persons who use a wheelchair. A few of the considerations that enhanced equal participation included:

- The building and all rooms, including the restrooms were wheelchair accessible.
- The table was rectangular but was set up so that all members could see each other's faces. This assisted the person who is deaf to lip read, if she choose.
- The room was well lit and had equal lighting in all areas. Again, this assisted lip reading.
- The person who was deaf was asked to choose her preferred seat first. The Deaf feel a greater confidence and comfort when they can choose a seat that is conducive for their participation. It is important that they can see and read the interpreter and the lips of the other members as best as possible. The interpreter was seated across from her with the convener seated next to the interpreter.
- The person who used the wheelchair also felt comfortable sitting across from the
  convener. She requested that the convener repeat her contributions if others had
  difficulty understanding her speech. This request is a good example that, given
  the opportunity, persons with disabilities will request the assistance they might
  require.
- At the beginning of the first meeting the convener set ground rules. For the sake of the person who was deaf, only one person would speak at a time. Before speaking, each participant was requested to raise a hand to be recognized. The convener would act as the referee.
- Even though it was not requested, audio enhancement equipment was available for persons who might have a hearing impairment.

Audio enhancement equipment includes various types of personal listening devices that amplify the sound for those with hearing deficits.

The adaptations required for this meeting were easy and natural and can assist all participants. Once the participants became used to the procedure they found it very comfortable. Some expressed that they preferred it to the typical meeting in which the strongest and the quickest person gets more speaking time and tends to dominate the meeting.

The focus group meeting was to accomplish the following goals:

- 1) To discuss the project in general, its purpose and its potential.
- 2) To advise on the content and methodology employed to create the website.
- 3) To critique and edit the Participant Questionnaire, the Prc-Survey, and the Post-Survey documents.
- 4) If willing, to scrve as on-going advisors and, perhaps, contributors to the website.

The first convening set the tone and procedure for all the subsequent ones. All meetings began with the same prayer, *The Beatitudes for People with Special Needs*. <sup>117</sup>
This was followed by introductions of those present. Next, the author distributed an abstract for review. It was originally believed that the four goals, listed above, might be accomplished in one meeting. The project concept itself became the topic of the first meeting. It is difficult to describe the level of enthusiasm demonstrated by the focus group. For one hour the participants discussed the benefits, and by the end of this time, were discussing possibilities that had not been imagined. One person saw the website as a vehicle for global communication in which visitors from different countries would share practices and suggestions. Every member was enthusiastic in his or her

<sup>117</sup> The Beatitudes for People with Special Needs. Date and publishing information unknown. A possible author may be Andre Masse, C.S.E. NAMR Quarterly (National Apostolate for the Mentally Retarded, 1968). The wording is different from the version used by the focus group, but this is the earliest dated version the author has found. See Appendix F for sample of *The Beatitudes for People with Special Needs*, as used by the focus group.

endorsement of the concept. The author had not anticipated this level of support. 118

Only Goals One and Two above were accomplished at the first meeting. As a result, another meeting was scheduled to accomplish the editing of the Participant Questionnaire and the Pre-Survey. In the end, it took two more meetings and much correspondence by email to accomplish these tasks. The initial enthusiasm turned to serious commitment to help create the website. Depending on the nature of the website being constructed, it would be important to set aside three or four occasions for face to face meetings with a focus group to accomplish the tasks.

Editing the surveys was more difficult than one might first expect. The focus group attempted to create surveys that would be understandable to persons with disabilities and to a general public who possess different levels of education, especially in the area of church teachings. Persons who are deaf have a unique challenge. Sign language is its own communication system, and the typical written American English is not always understood. It must be translated. The focus group attempted to accomplish this task without making the surveys sound condescending to any of the participants. 119

This was a working focus group that was willing to commit to the task. As the meetings progressed, the group decided to wait until the conclusion of the trial website. possibly September, to develop the Post-Survey. Members felt that once comments began to be gathered, an effective Post-Survey could be developed. They felt that the final survey should really evaluate the website.

<sup>118</sup> See Appendix G for agendas for two meetings and the meeting minutes for the first Focus Group Meeting.

<sup>119</sup> See Appendix H for Participant Questionnaire, Pre-Survey and Post-Survey.

In the meantime, the focus group became advisors to the project. Between February 2006 and May 2006 email correspondence replaced the face to face meetings. The author emailed correspondences to request advice on specific aspects of the website's construction. The major input involved the website domain name and suggestions as to what should be posted initially on the site after it was launched.

# **Choosing a Website Domain Name**

One area not considered as a major issue initially was the domain name. It is important to choose a name that corresponds closely with the contents of the site. Also, there is the question, "How will people find the website?" If they do a search, how does this particular site come up, at least, on the first page of the results? The domain name is one of the key considerations for these issues. The focus group discussed this issue by email. The goal was to choose the best name possible. They suggested several alternatives. Among them were:

- Letmein.org
- Mychurchtoo.org
- Accessthechurch.org
- *Top d* (Theological Options for Persons with Disabilities)
- Allarewelcome.org
- Dioceseteachingsondisabilities.org
- Disabilityinourdiocese.org
- Diocesedisabilities.org
- Teachingdisabilitiescatholic.org
- Teachingspecialdisability.org
- Teachingspecialpeople.org
- Catholic disability theology.org

The focus group came to the conclusion that trendy titles, such as the first two above, would not be appropriate. The greatest debate was over the words "theology" and "teachings." Members thought that "theology" might make people reluctant to visit. The

word might sound too intellectual. The author decided to combine the word "teachings" with the preferred domain name, *Catholicdisabilitytheology.org*. The focus group agreed that *Catholicdisabilityteachings.org* would present key words that people might search for in any order.

Agreement on the name was the first step. The author conducted a search to see if the name was available. Domain names are not arbitrary or simply made up and used. They have to be purchased and registered. In a way, it is a copyright on the name of the site and cannot be used by anyone else. The author discovered that \*Catholicdisabilityteachings.org\* was not available. However, \*Catholicdisabilityteachings.com\* was obtainable for purchase. This choice of selecting a .com for a domain name will be discussed further in the next section. It is important to note that the author can choose a domain concurrently with the choice of the website host, and this is the procedure he followed.

# Choosing a Website Host

As stated previously, there are many alternatives when selecting a website host.

The "host" is a company, in simple terms, that has large computers with a great deal of memory. The person who wishes to purchase some of this memory to host a website "rents" the space on a monthly basis. If the payment is not received, the website vanishes. The person still owns their website (the written, visual or audio material on the site) and domain name, but must find a new host on which to place the website.

After extensive research and consultation with companies that create websites, the company Verio<sup>©120</sup> was chosen. There were many reasons for this choice.

<sup>&</sup>lt;sup>120</sup> Verio<sup>©</sup> Inc. 1996-2006: An NTT Communications Company. http://www.verio.com. Internet.

- Verio reportedly supplied good technical support.
- It allowed for different packages that allowed the client to increase or decrease the size of the memory used for the website. Each increase, of course, is an additional fee.
- It allowed for frequent updates to the site. Many limit the number of changes in a single month.
- The contract was monthly. If unhappy with the service, the author could find another host and the site could be quickly transferred without interruption of service.
- It allowed for unlimited amount of visitors per month. This was important since it was unknown how many people might visit.
- It currently hosts the sites for Cleveland Catholic Charities Health and Human Services of the Catholic Diocese of Cleveland, Ohio.

An added benefit was that, on this website, there was a tool to search for the availability of domain names. It would show what name was available, using a combination of the suggested title. It would then detail whether the extensions "org," "com," "net," "gov," ect., were available. As it turned out, only \*Catholicdisabilityteachings.com\* was available at that time. Most people believe that the extension .com only refers to a for-profit organization. This is not the ease. Any of these extensions may be purchased by anyone, whether "for profit" or "not for profit." organization. In March 2006 \*Catholicdisabilityteachings.com\* was purchased. A place then existed for the website and an address existed for people to visit.

## Constructing the Website

Between February and May of 2006 the initial construction of the website took place. It is not possible to describe all the steps involved in the creation of a website. A few words in general will suffice. Still, it is important to understand that an author who creates his or her own website is taking on an enormous amount of work.

As stated, this author employed <u>Frontpage</u><sup>©</sup> as the program to create and manage the site. Website construction programs are user friendly and can be used by persons

who possess moderate word processing skills. However, there are differences in each website program that require acclimation. In many areas of the United States, there are centers that provide classes on specific programs. The website creator can also engage in on-line tutorials, requiring some patience. Each of the on-line tutorials for <a href="Frontpage">Frontpage</a> requires some five and one-half hours to complete. Between attending classes and taking the tutorials, the author spent approximately fifteen hours becoming familiar with the program prior to taking on the task of actually creating the website.

It is also important that the creator has a knowledgeable advisor to consult with on issues that arise. Ralph Joyce, mentioned previously, served in this capacity. Over the next nine months Ralph spent dozens of hours in person or over the phone providing advice and personal inservice on creating the site and consulting on issues that arose in its construction. In addition, Marilyn Scott, Program Administrator for Catholic Charitics Disability Services, volunteered to undertake the same orientation to learn the website program. Marilyn was an invaluable resource and partner in the construction and maintenance of *Catholicdisabilityteachings.com*.

There are basically two places to build the website. It can be constructed on line (on the actual internet site). One performs this task by accessing the site, entering the program, using a password, and editing the site there. This approach is not advisable. There are too many possibilities for errors in this method. First, the edits or additions can be made, but it is a difficult task because one is on line at the same time. The section one is editing appears on the website immediately, so there is not sufficient time for reflection and editing prior to publishing the site. The other danger is that if the host goes out of business, or the client fails to pay the monthly cost, the website is gone. All the material

on the site would disappear. Even if this calamity were not to happen, if the client were to choose to move the site to a new host, it would be very difficult to copy the site and mount it to a new location. Because of these difficulties, the author may also have problems with the copyright procedures.<sup>121</sup>

The suggested approach, and the one the author employed, is to build the site in one's own computer. One must be careful to save and to make copies of the information before publishing the material to the website. In this approach, errors can be minimized, editing can be performed in a thoughtful manner, and the published site can reflect the author's intention. While the current site exists on line, the revised site can be created in one's computer. When the results are seen as satisfactory the new website can replace the old site. The program used made the process of publishing the material very easy.

The content of the initial site was determined by two things. When the initial website was being constructed, material from Chapter 2 was used. The author assumed that certain subjects would be important. For example, the United States Conference of Catholic Bishops' *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities*<sup>122</sup> and other teachings of the church were essential elements to the mission of the website. Other topics were suggested in the Pre-Survey, which the author conducted during April and May of 2006. The date to launch the website online was June 1, 2006. There was not a great deal of time between receiving the surveys and publishing topics

<sup>121</sup> Copyrighting the website is not treated in this chapter, but to copyrigh1, the author must copy the website onto a disc and submit it to the Library of Congress. It is not a difficult task but must be resubmitted as "revised" when changes to the site are made. For more information visit "The U.S. Copyright Website" (Revised January 3, 2007, accessed January 4, 2007); Available from http://www.copyright.gov/register/literary.html; Internet.

United States Conference of Catholic Bishops, *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities* [publication on-line] (1978, accessed September 4, 2006); Available from http://www.ncpd.org/pastoral\_statement\_1978.htm; Internet.

that corresponded to the interest areas. As a result, the author dedicated a great deal of time during May 2006 to writing and creating sections of the website.

### Selecting the Survey Team

The author envisioned the survey team as a group of volunteers who would visit and evaluate the website during the five months from June to October 2006. The methodology for selecting the members was through an evaluation of an initial Participant Questionnaire that each perspective member would complete. The selected members would then complete a Pre-Survey to determine topics of interest. After the website launch, the author emailed each member a few short questions each month to focus attention on various aspects of the site. In October 2006 each member completed a Post-Survey to evaluate the site against the four goals mentioned at the beginning of this chapter. It should be noted that the focus group had input in refining this methodology. Several of these steps arose as suggestions from the meetings with them. Two were most notable. The first was to send monthly reminders with questions to the participants. This was to be a way to remind the participants to visit the site and to keep them focused. The second suggestion was not to limit the number of participants in the survey team.

When the author first proposed this project, he had hoped to assemble one hundred people to be part of the survey team. The focus group suggested that the number not be limited so as to allow as many people to participate as possible. At the same time, one member of the Advisory Committee from the St. Mary Seminary and Graduate School of Theology made a similar suggestion. The author had feared initially that one hundred people would not be found to participate in such a task. The focus group and the advisors displayed a greater confidence at the interest people would show toward this

project. 123

In March 2006 invitations to be selected for the one-hundred-person survey team were sent out. The potential candidates initially included:

- The Disability Services Newsletter list --- 2,561 persons by U. S. Mail.
- The Disability Services E-Newsletter list --- 917 persons by email.
- All priests in the Catholic Diocese of Cleveland --- 236 persons by fax.

A total of 3,370 persons were contacted directly. As the invitation disseminated, people responded with requests to share the information with others. During the following month the author contacted the superiors of religious congregations. In total, as many as 4,000 people may have been contacted. The goal was to select the survey team by April 2006.<sup>124</sup>

The invitation's cover letter specifically mentioned that only one hundred persons would be selected. The responses quickly changed the composition of the team to reflect the wishes of the focus group and the advisor. A total of 399 persons responded (11% of the total). Of these, 317 persons wished to participate, and fifty-seven persons declined. Another twenty-five persons called to say that they would not be able to participate. The vast majority of those who declined stated that they would like to participate but did not have access to a computer. All stated that they thought that the project was very valuable and needed.

The decision to include all 317 persons in the survey team came down to the quality of the responses. It became too difficult to choose participants. Many

Woost, member of the Advisory Committee from the St. Mary Seminary and Graduate School of Theology also felt that the survey team should include everyone. It was a wise decision. The author had not foreseen that there would be a substantial attrition over the course of the project. This issue will be discussed in chapter 5.

<sup>124</sup> See Appendix H.1 for the invitation to participate in the project and the Participant Questionnaire.

questionnaires arrived with several pages attached, typed or handwritten. These additional pages were all explanations of why the author should select that individual. Similar to the focus group's initial reaction to the project, the responses were overwhelming in their desire to be part of the creation of the website. It is interesting to note that such long responses mainly came from laypersons, especially women. There were a few priests and religious who voiced similar sentiments. For the most part, priests and religious simply filled out the questionnaire and added no comments. Interpreting the meaning of this clerical paucity of response is up to the reader. Needless to say, the author accepted all 317 persons into the survey team.

At the end of April 2006 the Pre-Survey was emailed or mailed to the 317 members. The participants were instructed to return the survey by mid-May. The Pre-Survey contained statements to measure the participants' level of knowledge on church teachings pertaining to persons with disabilities. The author then asked qualitative questions that allowed the participants to suggest topics for the website. The author would use this information to construct the initial website. Chapter 4 presents a detailed analysis the demographics of the survey team as well as the results of the Participant Questionnaire and the Pre and Post-surveys. It is important to underscore the value of the survey team in the construction of the website.

### Launching the Website

To meet objectives, it is important to follow the project chart's time lines. The anticipation of the survey team appeared high. The author felt great pressure in May of 2006 to create a website that was not a disappointment to the survey team. This is not to say that the website should be perfect. Quite the contrary, it was important to present a

website that was a good start but incomplete. One of the goals was to create an interactive site. To accomplish interactivity, the survey team must feel an ownership in the website. The author hoped to achieve this goal by encouraging the participants to help create the site. The methodology for accomplishing this assistance was not clear at this point. The author hoped that the survey team would determine how the website would develop during the five month trial period. Their suggestions would enhance the site and make one that the visitor could identify with. On June 1, 2006 the website *Catholicdisabilityteachings.com*, was launched.

### **Enhancing the Website**

When this project was originally proposed to the advisors at the St. Mary

Seminary and Graduate School of Theology, the author proposed that the trial period
would last from June to December, 2006. The initial creation of the site progressed so
well that the trial period was shortened so that it would end in October, 2006. Several
considerations prompted this decision. The skills needed to create and maintain the site
developed more quickly than anticipated. As a result, the initial website was created and
refined faster than expected. Second, after considering the size of the survey team, the
author determined that such a long trial period would risk losing their interest. Lastly,
considering the amount of data from the surveys that needed to be analyzed as well as
completing the written narrative of this project, the timeline (project chart) was modified.
It is wise to re-determine one's methodology in order to accomplish the goals of the
project.

As suggested by the focus group, beginning in June 2006, the author emailed or mailed the survey team monthly reminders to visit the site. These initially included two

or three short questions to direct their attention. The team was not obligated to reply.

The actual months for enhancements to the website occurred between June and

September 2006. The monthly reminders did serve as a convenient way to routinely

contact the survey team to keep their interest. It also encouraged communication which
helped achieve the goal of making the site interactive.

One important consideration was to allow each member of the survey team to view the same website. This was accomplished by only republishing a new site at the beginning of each month. In this way, a person who visited anytime during that month was viewing and commenting on the same site. This technique also gave time to add to or edit the website in the computer and to reload it on to the internet at one time. The revised website was re-edited based on the monthly input from the team. The author posted the monthly comments on the website as well. This allowed the team members to react to each other. 125

Throughout the trial period, the overall comments were consistently positive. The enthusiasm of the team was very impressive. Whether priest, religious or lay person, each subgroup of participants was very positive and continually endorsed and encouraged the ongoing development of the site. Basically, the members expressed their belief that the website has a value and that it was forming a new ministry to persons with disabilities. Several people wrote that they had no idea that the church had such strong teachings about persons with disabilities, or that there were so many possible ministries

This created an interesting effect. As the months progressed, some participants strongly disagreed with each other. The most interesting discussion was when the author posted definitions of different disabilities. Even though some of the team had requested this, others were very opposed. It is interesting to observe people who have the same goal arguing over what information is valuable to attain the goal.

available. One person wrote, "A person might never guess there is so much help available!" 126

There was, as well, an ample share of suggestions and constructive criticisms.

These comments were most common in June, July and August, in that order. The sharpest criticism came in June from persons who are blind or have low vision (visual impairment). The original website, for them, was too dark, the font was too small and there were not accessible features built into the site. This series of problems became a major challenge for enhancing the site. This challenge is still ongoing since there are many techniques to make the site user-friendly to a reading machine. The author still needs to acquire this knowledge. As a result of these comments, during the first month the website was totally redesigned. On July 1, 2006 a new site was published. The team was amazed. It appeared to them that a new website had been created overnight.

The majority of suggestions dealt with items that should be added to the site. The participants clearly indicated that they wanted much more information. Trying to keep up with the requests became overwhelming. By August most of the participants had become very comfortable in the process being utilized. It had become obvious to them that, with the amount of additions occurring each month, the author was spending an extensive amount of time editing the site. Several began to write, "Don't try to do everything all at once." This is good advice to anyone who attempts a similar project.

<sup>&</sup>lt;sup>126</sup> M. S., Email Correspondence, July 6, 2006.

<sup>127</sup> A "Reading Machine" is one name for a device that scans and electronically "reads" a page of 1ext. At present these devices only read from left to right so they do not make allowances for techniques such as columns, graphs or pictures. On the internet, hidden commands must be placed for the reading machine to operate effectively.

 $<sup>^{\</sup>rm 128}$  See Appendix I for a synopsis of the comments made during June, July and August of the project timeline.

The completion of the website is not the goal. The process of developing it along with the team is the actual goal. The overall process and the interaction of the visitor with the author are more important than the amount of material produced.

This last point is very important. To create an interactive website, communication with the team is crucial. The author should reply to each comment received as soon as possible. It is time consuming, but even a short "Thank you for your suggestions" gives the participants the feeling that they are being heard and taken seriously. There will be visitors who will require a lengthier response. As the months elapsed, more and more people asked for comments or suggestions to personal questions or issues in their life. The author took time to respond to these in depth. This is the methodology for creating the interactive aspect of the site. The internet is a very impersonal medium. Many websites present information. However, most do not interact with the visitor in a timely manner. To communicate in an appropriate fashion demonstrates a caring atmosphere. It lends an air of support and hope that simple facts on a website cannot convey. More than any of these things, responding to people begins to fulfill the mission of the website. The purpose of Catholic disability teachings.com is to be a door of hope. The assistance that is needed may not be found in website information. The site may provide an opening for people to communicate with a human being. In this way, the website reaches out to people and extends the church's mission into a new terrain.

# Promoting the Website

Promoting the website, in forms of publicity to attract new visitors, was not seen as a goal at the inception of this project. In the process of developing the site during June the author became aware that promotion would be important. Since the survey team

included national organizations, publicity for the website began immediately and without the initiation of the author. Almost simultaneously with the launching of the site, the organizations that were participating requested permission to highlight the site on their own websites. While this promotion occurred, other websites contacted the author to do the same. Soon there were numerous sites that were encouraging people to visit *Catholicdisabilityteachings.com*. When more websites linked to this site the position of *Catholicdisabilityteachings.com* began to climb on search engines.

After that, articles began to appear on the internet highlighting Catholicdisabilityteachings.com. Some requested permission, but others simply published articles and linked to the site independently. As a result, the author is unable to determine how many sites have mentioned and linked to Catholicdisabilityteachings.com. The evidence that the word was spreading was that the initial group visiting the site was expanding. Soon email began arriving from different parts of the United States. People had read about the site on internet newsletters and websites. On June 30, 2006 the Catholic Universe Bulletin, the Catholic newspaper for the Catholic Diocese of Cleveland, published an article on the website. The publicity increased even more due too these events.

By July 15, a person emailed to report that the website was coming up number one on <u>Google</u><sup>©</sup> when she entered "Catholic Disability Teachings," into the search engine. <sup>130</sup> This outcome is important so that when people are searching for this type of

<sup>&</sup>lt;sup>129</sup> Dennis Sadowski, Editor. *Catholic Universe Bulletin*. Vol. 132, No. 26 (Cleveland Catholic Diocese, June 30, 2006). See Appendix J for the reprint of this *Catholic Universe Bulletin* article.

<sup>130</sup> Catholic disability teachings.com was also coming up on the first page of search results for the Dogpile [http://www.dogpile.com] and Yahoo [http://www.yahoo.com] search engines. This means the website was coming up in the first ten results of these searches. One advisor had related that the goal of "search optimization" was to get a website onto the first page of search results. They were amazed that the

information, the website is prominent. Several website consultants were asked how a website this new could be coming up so high in search engines. It was stated that what makes a site score high is not the number of visitors to the website but the number of websites that have put up a link to that site. In other words, so many websites had linked to *Catholicdisabilityteachings.com* that it was coming up number one on search engines in only six weeks. By August it was difficult to determine whether the email being received was from the survey team or not. The participants had grown into a much larger group.

Beginning in July, more and more parishes in the Catholic Diocesc of Cleveland began printing articles about the website in their parish bulletins. They published these articles to assist families in their parishes who had a child with a disability. A few stated that this practice was a way to give hope. By October 31, 2006, approximately 2,317 persons had visited the website. On the average, over four hundred and fifty persons were visiting the website monthly. It is obvious that the aspect of publicity is a very important consideration when creating a website.

A website is an ongoing project. A good interactive site continues to evolve with new needs and interests of the visitors. New visitors keep the site fresh with their interests. Allegorically, a website is a village that can promote community and create unity rather than division. It can form a welcoming community.

This chapter has explored important aspects of the methodology of this project.

website was coming up in searches on the first page after such a short period of time. Website creators often spend thousands of dollars to have companies optimize their position on search results.

<sup>&</sup>lt;sup>131</sup> This is an approximate number. On September 1, 2006, when reposting the site, the number counter was set improperly. Five hundred and fifty-four visitors had not been counted. When the counter was reset it was set to a conservative estimate.

The success or failure of the project will be determined by statistical analysis of the data gathered from the survey team. This information will be presented in Chapter 4.

#### **CHAPTER 4**

# SUMMARY AND ANALYSIS OF SURVEY DATA

The objective of this project is to create a user-friendly website to assist the various target groups to access Catholic teachings and pastoral suggestions, with a view to assisting the person with a disability to participate as fully as possible in church life. It is simply one new means to an end. Chapter 3 presented an overview of the various methodologies that were employed in building the website. This chapter will provide specifies on the survey team which volunteered to submit personal demographic information. The team completed a Pre-Survey which reviewed the survey team's knowledge of church teachings and gave them an opportunity to suggest topics for the website. They further agreed to visit the website for five months to analyze the site's progress. At the end of this trial period they completed a Post-Survey which provided an opportunity for them to evaluate the website in accomplishing its goals.

The survey data was crucial to this project. It is from this data that the website was initially constructed and refined throughout the timeline of the project. For this reason, this chapter is divided into four parts. The first part will present the quantitative data gathered in the "Participant Questionnaire." Part Two will present the qualitative data drawn form the Pre-Survey and comments made by people who visited the website during the five month experiment. Next, the results of the Post-Survey and the evaluation of the website will be presented. Lastly, the author will present conclusions on the success or failure of this project.

# Part 1: Quantitative Data: Demographic Information 132

Three hundred and seventeen people initially volunteered to be part of the survey team. There were 98 males (31%) and 219 females (69%). (Table 1)

Respondents by Gender

Respondents by Gender

80%
70%
59 60%
59 50%
8 40%
8 20%
10%
0%
Fenale

Male

Table 1. Respondents by Gender

The overwhelming female to male race composition was "white" (89% of the females and 96% of the males). "African Americans" were the next largest group (7% of the females and 1% of the males). "Hispanic" females and males comprised two percent of the respondents while, "Asian/Pacific Islanders" composed only a fraction of the team (1% of the females and none of the males). One percent of both the males and females chose not to answer the question (Table 2).

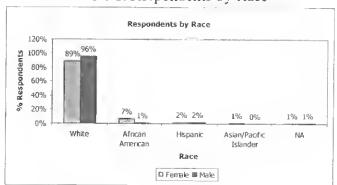


Table 2. Respondents by Race

The age range among the team members was surprising. The largest age category

<sup>&</sup>lt;sup>132</sup> See Appendix H.1 for the Participant Questionnaire which was the basis for the demographic information.

for both females and males were those between fifty and sixty-nine year old (50% of the females and 58% of the males) with the next largest group being those between thirty and forty-nine years of age (40% of the females and 32% of the males). These two groups present an important demographic niche, representing individuals born between 1937 and 1974. Many of these individuals were part of the disability rights movement. Many of them experienced a time when there were little or no supports for persons with disabilities in society. This group also presents a pre- and post-Vatican II religious mentality. Expectations of the church and authority may vary due to the religious upbringing of this particular demographic.

The smallest group to respond was those members over the age of seventy. This result is not surprising. Internet use is stronger with people under this age. Even though interest was voiced by many other older individuals, those from the over seventy group who replied stated that they did not have access to a computer. This outcome is unfortunate since many in this group have had the experience of raising a child with disabilities during a longer time when few formal services were present in society. Church ministrics were difficult to find, as well. This age group was instrumental in achieving many of the advances that persons with disabilities have achieved today. The advocates with the greatest experience would be a small part of this study (Table 3).

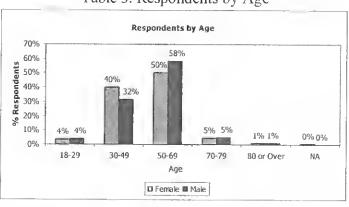


Table 3. Respondents by Age

The author assumed that the ideal group to critique this sort of website would be one that had a diverse experience of disabilities and were familiar with at least one disability area. The demographics demonstrated that this goal was accomplished. When asked to describe themselves, respondents could choose as many descriptions as applied. The group varied widely in self-description, but the overwhelming majority were persons who were related to or who worked directly with a person (or persons) with a disability. This characteristic would add life experience to the evaluation of the website and would challenge the site to speak to personal issues from a church perspective. Only seven people admitted no experience in the disability field.

Among the target groups for whom this website is intended were priests and those in ministry. It is important to include them in the survey team. Some two hundred and thirty-six priests were initially contacted to participate. Twenty-seven volunteered to be members of the team. This number constitutes an eleven percent response from this group, which finally included two bishops. In addition, three religious brothers, four deacons, nineteen religious sisters, and eighteen pastoral ministers joined the team.

These individuals comprised twenty-two percent of the entire survey team.

The author was most interested in including persons with disabilities in the survey team. It is important to include the persons for whom a website is ultimately directed. Forty-four people (14% of the team) identified themselves as a person with a disability. This subgroup of the team was composed of thirty women (20% of the women) and fourteen men (14% of the men). The disabilities included physical challenges (14), mental illness (9), hard of hearing (6), multiple challenges (3), blind/visually disabled (4), deaf (2), Autism (2), cognitive disability (4), and Attention Deficit Hyperactivity Disorder (ADHD) (1). The "other" category included persons with fibromyalgia syndrome (FMS)<sup>133</sup>, arthritis, and chronic fatigue syndrome. The "other" group was composed of persons with challenges that could be considered forms of a disability since the impact lessens the person's quality of life and ability to live in a typical manner. Each of these challenges would call for some sort of accommodation by the church in order for the person to participate fully.<sup>134</sup> Table 4 demonstrates the diversity of the survey team.

<sup>&</sup>lt;sup>133</sup> FMS (fibromyalgia syndrome) is a widespread musculoskeletal pain and fatigue disorder for which the cause is still unknown. Fibromyalgia means pain in the muscles, ligaments, and tendons – the soft fibrous tissues in the body. For further information visit the Fibromyalgia Network (ND, accessed October 30, 2006); Available from http://www.fmnetnews.com/pages/basics.html; Internet.

<sup>134</sup> Society defines certain challenges as "disabilities" to categorize people for services throughout life. Certain conditions that are in reality real challenges are not diagnosed as a disability because they do not fit any category.

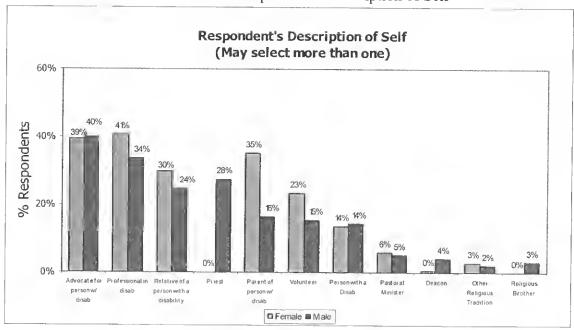


Table 4. Respondent's Description of Self

Lastly, on the "Participant Questionnaire," respondents were asked with which type of disabilities they were familiar. The author would use this information to determine the approach the website might take initially. This information would also give greater insight about the person who would be visiting the site and his or her particular interest area.

As with the self descriptions, this question demonstrated a great variety of responses. Most people were familiar with cognitive disabilities (246 people). Physical challenges and autism came in second and third. Overall, the diversity of the survey team indicated that the interest areas would vary radically and that the website would have to address general issues that applied to all these groups (Table 5).

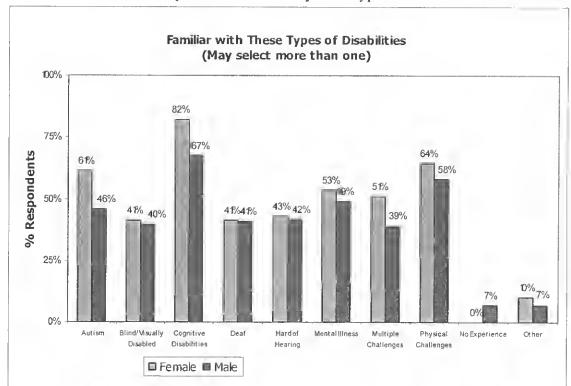


Table 5. Respondents' Familiarity with Types of Disabilities

### Part 2: Qualitative Data

One goal of this project was to determine the survey team's level of knowledge of church teachings pertaining to persons with disabilities. The author also needed to ascertain the information that the team felt should be present on the website. In other words, what would assist persons with disabilities to be further integrated into the life of the church? What would be helpful?<sup>135</sup>

To accomplish the goal of determining interest, the author sent a Pre-Survey to the survey team members. <sup>136</sup> It was a combination of open-ended questions as well as

<sup>135</sup> It should be noted that, while 317 people volunteered, many others who visited the website submitted suggestions. These were people who will be uncounted in the survey process, but their input was captured in more informal communication during the project. As a result, these individuals will be discussed in Chapter 5.

<sup>&</sup>lt;sup>136</sup> See Appendix H.2 for a sample of the Pre-Survey.

specific questions to be rated on a Likert scale.<sup>137</sup> As stated on the form itself, the purpose of the Pre-Survey was to gather information that supported the overall purpose of the project:

- 1. To determine the participants' level of understanding of church teachings and pastoral practices in the area of ministry to persons with disabilities.
- 2. To determine the type of information that a theological and pastoral website should provide.
- 3. To provide information that would assist persons with disabilities, families, priests, and pastoral ministers, among others to further enhance an understanding of the church's acceptance of persons with disabilities into the life of the church.
- 4. To provide an interactive medium that could adapt to new questions and needs.

The team members were first asked to respond to five statements. These statements were to determine the participants' knowledge of church teachings concerning persons with disabilities and their feeling as to the value of a website to present these teachings. Responses were based on a Likert scale of 1 to 5 (I=Strongly Disagree, 2=Disagree, 3=Neither Agree or Disagree, 4= Agree, 5= Strongly Agree) and were made in response to the following statements:

- 1. I think persons with disabilities feel accepted in the church.
- 2. I feel familiar with church teachings regarding persons with disabilities
- 3. If asked advice on a specific question regarding the place of persons with disabilities in the church, I would feel confident to know where to find the church's position.
- 4. I think that a website of theological and pastoral information would assist people in better understanding the church's position.
- 5. I think that such a website would be of value to me.

help get at the emotional and preferential responses people have to a design. This technique presents a set of attitude statements. Respondents are asked to express agreement or disagreement of a five-point scale. Each degree of agreement is given a numerical value from one to five. Thus a total numerical value can be calculated from all the responses. The benefits of a Likert scale are presented on the "Evaluation through Surveys," The Idea Website (N.D., accessed February 11, 2007); Available at http://www.i-d-e-a.org/page102.html; Internet.

### Overall Results of the Pre-Survey

The overall responses from all the participants showed variation between their feelings about present church integration efforts (Statement 1), the current church teachings on persons with disabilities (Statement 2 and 3) and the need for a website to promote further integration (Statement 4 and 5). As noted in Table Six, below, the overall responses for Statements 1, 2 and 3 demonstrate uncertainty. When responding to the statement "I think persons with disabilities feel accepted in the church," (Statement 1), an almost identical percentage of people agreed and disagreed, with the majority of the responses being unsure (neither agree nor disagree). The same uncertain responses were given to the statements "I feel familiar with ehurch teachings regarding persons with disabilities" (Statement 2) and "If asked advice on a specific question regarding the place of persons with disabilities in the church I would feel confident to know where to find the church's position" (Statement 3).

When statements turned to the value of a website, the responses agreed much more. The vast majority strongly agreed to the statements "I think that a website of theological and pastoral information would assist people in better understanding the church's position" (Statement 4) (55%) and "I think that such a website would be of value to me" (Statement 5) (47%). The remaining majority (33% and 34%) agreed with the statements while only few (5% and 4%) either disagreed or strongly disagreed. This result is not surprising when one considers that the participants who volunteered to be part of the survey team were aware that the project was to construct a website (Table 6).

Table 6. Total Responses to the Five Statements of the Pre-Survey

		Statement #									
		1		2		_ 3		4		5	
Response	#	%	#	%	#	%	#	%	#	%	
Strongly Agree	12	5%	26	11%	23	9%	136	55%	115	47%	
Agree	62	26%	83	34%	68	28%	82	33%	84	34%	
Neither Agree or											
Disagree	100	41%	51	21%	47	19%	15	6%	34	14%	
Disagree	61	25%	62	26%	77	32%	7	3%	5	2%	
Strongly Disagree	6	2%	21	9%	28	12%	6	2%	6	2%	
Total Responses	241	100%	243	100%	243	100%	246	100%	244	100%	

It is evident that there is uncertainty in responding to Statements 1 to 3 and an overall unanimity in the responses to Statements 4 and 5. Would there be a difference if the responses were divided into the subgroups (priest, parent, deacon, and so on)? This difference could be important in understanding the mindset of the different groups and the information or the approach that was needed on the website. <sup>138</sup>

# Subgroup Responses to the Pre-Survey

The data revealed the overall lack of deviation among groups with remarkably similar responses from each. However, there were different opinions on the present church approach to persons with disabilities.

When responding to the statement "I think persons with disabilities feel accepted in the church" (Statement 1), the negative responses came from unexpected sources. The author was not surprised that persons with disabilities disagreed or strongly disagreed with the statement (46%) but was surprised that forty-two percent of the priests, forty-four percent of the pastoral ministers, and fifty-three percent of the religious sisters felt that persons with disabilities do not feel accepted in the church.

 $<sup>^{138}</sup>$  See Appendix K for a table detailing the responses by the subgroups to the five statements of the Pre-Survey.

The author compared these groups with those who are personally or professionally related to persons with disabilities. These individuals have more daily contact with the latter group and might know their feelings about church acceptance. Of these subgroups, only thirty-one percent of the parents of a person with a disability, thirty-one percent of advocates, nineteen percent of the relatives, and nineteen percent of those who considered themselves "professionals" in the field of disabilities felt that persons with disabilities do not feel accepted in the church.

The author included Statements 2 and 3 to determine the participants' knowledge of church teachings pertaining to persons with disabilities. The statements "I feel familiar with church teachings regarding persons with disabilities" (Statement 2) and "If asked advice on a specific question regarding the place of persons with disabilities in the church I would feel confident to know where to find the church's position" (Statement 3) drew predictable results from the ministerial groups, but mixed results from others. Pastoral ministers were most confident (69% "strongly agree" or "agree" with both statements) that they were both familiar with church teachings and could give the church's position on the place of persons with disabilities in the church. Priests responded positively (56% "strongly agree" or "agree" to Statement 2 and 62% "strongly agree" or "agree" to Statement 3), but it is important to note that thirteen percent of them expressed a lack of knowledge and thirty-three percent (Statement 2) and twenty-one percent (Statement 3) could not agree nor disagree that they knew the church teachings concerning persons with disabilities. On the other hand, persons with disabilities asserted a surprising level of knowledge of these teachings (54% "strongly agree" or "agree" with Statement 2 and 36% "strongly agree" or "agree" with Statement 3).

The greatest unanimity was expressed in response to Statements 4 and 5, but the responses differed between those in ministerial roles and those who did not have ministerial responsibilities. When responding to the statements "I think that a website of theological and pastoral information would assist people in better understanding the church's position" (Statement 4) and "I think that such a website would be of value to me" (Statement 5), the strongest numbers of "strongly agree" or "agree" came from pastoral ministers (100% to Statement 4 and 94% to Statement 5), priests (88% to both statements), persons with a disability (86% to both statements), and parents of a person with disability (87% to Statement 4 and 86% to Statement 5).

Negative responses to these statements were voiced by several groups. Religious sisters expressed the most negative responses, disagreeing or strongly disagreeing with Statement 4 (6%) and 5 (19%). Another sixty-nine percent of the religious sisters expressed uncertainty as to the value of the website. The parents of a person with a disability demonstrated a slight uncertainty as to its value. Ten percent disagreed or strongly disagreed that the website would have a value (Statement 4) and seven percent did not think the website would be of value to them personally (Statement 5).

Overall, the value of the website seemed to be viewed differently, depending on the presence of a person with disabilities in the life of the respondent. The closer the relationship, and their personal experience of the church, appeared to influence these responses greatly. The website challenges the author to respond to the various groups and needs that may be expressed. Opinions on the church and its present efforts to integrate persons with disabilities vary widely, even within specific subgroups.

### Overall Selection of Topics for the Website

Part B and C of the Pre-Survey determined the direction the website would initially take. These sections measured the areas of interest for each subgroup. Would the areas of interest show diversity or unity?

Part B was an open-ended question. These subjective responses will be presented after the objective selections of part C. In part C the respondent could choose from eleven topics. The author chose these topics primarily from the areas presented in Chapter 2. The participants could choose as many topics as they wished.

The author gave the participants the following instructions: "Below, I have listed a few possible topics that could be included in this website. Please check as many as you think would be important to include." The choices were:

- 1) The Catholic Church's teachings on persons with disabilities and their place and/or role in the church.
- 2) The rights of persons with disabilities regarding the Sacraments.
- 3) Canon Law (the laws of the church) and what they say about persons with disabilities participating in the Sacraments.
- 4) Practical suggestions to assist persons with disabilities to participate more fully.
- 5) Disability etiquette (How to act around persons with disabilities when you first meet them).
- 6) How the church's social justice principles apply to persons with disabilities.
- 7) Current attitudes toward persons with disabilities and their historic causes.
- 8) Current studies & surveys on the quality of life of persons with disabilities.
- 9) Links to other websites that deal with disability issues and information.
- 10) How to develop an accessible church, one that is physically, sacramentally and attitudinally accessible.
- 11) Information concerning a specific disability.

Overall, the participants expressed interest in a website that contained all the suggested topics. All respondents showed strong interest in the church's teachings (95.9%), practical suggestions to assist persons with disabilities to participate more fully in church life (95.1%), and sacramental accessibility (93.9%). The lowest number of

votes was cast for those that dealt with the history of current attitudes, surveys on the quality of life of persons with disabilities, and topics dealing with specific disabilities. It should be noted that even these topics were chosen more than fifty percent of the time. The author assumed that these choices indicated a desire to understand the teachings of the church and to acquire practical advice on the further integration of persons with disabilities. The selected choices, in order of priority, can be found in Table 7.

Table 7. Overall Selection of Topics for the Website

Total Respondents = 244		
Possible Topic	#	. %
The Catholic Church's teachings on persons with disabilities and their		
place and/or role in the Church.	234	95.9%
Practical suggestions to assist persons with disabilities to participate		
more fully.	232	95.1%
The rights of persons with disabilities regarding the Sacraments.	229	93.9%
How to develop an accessible church: one that is physically,		
sacramentally and attitudinally accessible.	221	90.6%
Links to other websites that deal with disability issues and		
information.	215	88.1%
Canon Law (the laws of the church) and what they say about persons		
with disabilities participating in the Sacraments.	183	75.0%
How the church's social justice principles apply to persons with		
disabilities	181	74.2%
Disability etiquette (How to act around persons with disabilities when		
you first meet them).	181	74.2%
Current studies & surveys on the quality of life of persons with		
disabilities.	138	56.6%
Information concerning a specific disability.	127	52.0%
Current attitudes toward persons with disabilities and their historic		
causes.	123	50.4%

# Subgroup Selection of Topics for the Website

The subgroup responses showed great deviation among them. The first choice and the last choice of each group varied among topics. As a result, the responses were difficult to interpret. Most subgroups tended to choose "Catholic Teachings" and "Practical Suggestions" among their top choices. Parents and religious sisters chose "The

Rights of Persons with Disabilities Regarding the Sacraments" as their number one choice. Priests chose this subject as their last choice. "Canon Law" was the most consistent topic being chosen as the one of the middle choices (selection 3 or 4) by most groups. No one in the Deacon, Other Religious Tradition, or Religious Brother subgroups voted for Canon Law. Persons with disabilities chose "Canon Law" as their third choice (9%). It is noteworthy that priests voted "Canon Law" as the forth choice (7%). 139

The most infrequently chosen topics were "Current Attitudes," "Current Studies and Surveys," and "Information Concerning a Specific Disability." This phenomenon was fairly universal, but there were variances here as well. For example, persons with disabilities chose "Current Studies and Surveys" as a second choice, as did religious sisters, and those in the Other category. "Disability Etiquette" was interesting to observe among the groups. This topic appeared to take a different position in the groups' rankings, depending on personal experience of the respondent with individuals with a disability. The more experience the person had, the less interest they showed in this topic. Most other groups placed this response in a middle position. For example, priests chose this category as their forth selection (7%), tying it with their choice of Canon Law. Parents and relatives chose it as one of their last choices, while professionals chose it as their first choice. From these results, the author concludes that the respondents chose this category because of either the personal need to feel comfortable in the presence of a person with a disability, or because of a their belief that this subject is important to present to others.

<sup>&</sup>lt;sup>139</sup> See Appendix L for the detailed responses by each subgroup to Part C of the Pre-Survey.

Even though the results were mixed, the author found the divergent opinions valuable. It is important to remember that the interests of people vary radically, depending on their life situations. The examination of the subgroup responses reveals little in terms of unique overall preferences. Most groups were interested in practical suggestions and church teachings as the primary common interest areas. These are topics that the website should offer immediately. Table 8 demonstrates the diversity of the subgroup responses.

Table 8. Subgroups Prioritization of Website Topics

Website Topics by Choice (Blank spaces indicate no votes cast for these items)	Other  Religious Brother  Religious Sister Other Religious Tradition Deacon  Pastoral Minister	2 2 2	- Indicate of the state of the	oups	2		m m	t We	ebsite	4 - 1 - 1 - 1 - 1 - 1 - 1 - 1 - 1 - 1 -	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	
	Relative Professional	4	2 3	4	ω .v	1 6	5 2	7 9	7	9	-	-
	Priest	m	\ \n	4	23	4	2		4	1 2	4 5	-
	Person w/ disabilities	m	2	m	4		4	5	64	~	-	+
	Volunteer	7	'n	4	_	m	m	4		4	9	T
	Advocate	m	2	4	3	'n	9	_	7	4	2	1
	Parent	77	-	641	4	7	5	∞	9	4		1
		The Catholic Church's teachings on persons with disabilities and their place and/or role in the church.	The rights of persons with disabilities regarding the Sacraments.	Canon Law (the laws of the church) and what they say about persons with disabilities participating in the Sacraments.	Practical suggestions to assist persons with disabilities to participate more fully.	Disability etiquette (How to act around persons with disabilities when you first meet them).	How the church's social justice principles apply to persons with disabilities.	Current attitudes toward persons with disabilities and their historic causes.	Current studies & surveys on the quality of life of persons with disabilities.	Links to other websites that deal with disability issues and information.	How to develop an accessible church, one that is physically sacramentally and attitudinally accessible.	Information concerning a specific disability.

### Overall Subjective Selection of Topies for the Website

Part B of the Pre-Survey allowed the participants to voice their interests before the objective choices were presented in Part C. The participants could submit as many suggestions as they wished. The author gave the participants the following instructions, "Now I would like to know what you think would be important to include on this website. In the space below write any suggestions that you can think of."

Eighteen percent of the respondents (43 people) did not submit any suggestions outside of the ones given in Part C. The more popular volunteered topics were:

- The location of special religious education classes
- The location of accessible churches in the Catholic Diocese of Cleveland
- Recreation activities/respite
- Community resources
- Parish activities
- How to start a parish advocacy program
- Theological information

# Subgroup Subjective Selection of Topies for the Website

The majority of topics submitted for Part B reiterated the topics in Part C and demonstrated no uniqueness among the subgroups except for one. The topics listed above were submitted almost exclusively by the non-clergy subgroups. The responses demonstrated a difference in mindset between priests and almost every other group, especially parents, when it came to stating topics that would promote the integration of persons with disabilities into the church.

It appears from the data that priests define "access to church" in mainly theological, liturgical, and sacramental terms, while parents tend to think much more globally in reference to church life. Parents define an inclusive church in terms of their

personal obstacles and priorities. They demonstrate a concern for the whole life domain and needs of the person with a disability. This concept includes liturgical and sacramental inclusion, but parents express a concern to participate in all other facets of the church community, as well. These participants felt that all of church life, both sacramentally and socially, should be completely open to persons with a disability. It is only with complete participation that they would then consider the church "accessible."

On the other hand, the concerns of priests appeared narrower. Consequently, one could posit a communication issue between parents and priests. Twenty-two priests (92 %) submitted comments for Part B of the Pre-Survey. Their responses expressed concerns with church documents, sacramental access, catechetical access, issues of Canon Law, and the determination of appropriate reception of the sacraments. There were two exceptions. Two priests who also identified themselves as a "relative of a person with a disability" shared many of the concerns of the parents. Overall, however, the data indicates that the mindset of priests tends to focus on single issues rather than global ones. Sacramental access is seen as the same as an accessible church. This point of view presents a challenge to the leadership of the church to listen and understand the spiritual and social needs of persons with disabilities and their families. This situation also challenges the website to ereate a common ground for communication among these diverse viewpoints.

#### Part 3: Post-Survey Evaluation of the Website

The website was launched June 1, 2006. For five months the author sent the participants monthly questions and directed them to critique the website as it was

developed. On October 1, 2006 participants received a Post-Survey. One hundred and ninety persons responded by the due date of October 16, 2007. 140

The author asked the team members to respond to eight statements. They were then given two open-ended questions. Lastly, the team members could answer one yesno question to determine their continued involvement in the website. <sup>141</sup> The responses to the eight statements will be considered first.

A Likert scale of one to 5 measured the responses to the eight statements.

(1=Strongly Disagree, 2=Disagree, 3 =Neither Agree or Disagree, 4= Agree, 5= Strongly Agree). The members could react to the following statements:

- 1. This website was easy to use.
- 2. I found the material on this website easy to read and understand.
- 3. I was able to find the information I was interested in or searching for.
- 4. My appreciation of Church's teachings and pastoral practices in the area of ministry to persons with disabilities has increased due to this website.
- 5. I feel that my suggestions and input helped shape the information contained on this website.
- 6. I think that the website assists people in better understanding the Church's teachings regarding persons with disabilities.
- 7. This website is of value to me.
- 8. 1 plan to visit this website as a source of information in the future.

This survey determined the success or failure of the site to achieve the goals of the project. The Post-Survey would measure three evaluative goals previously listed:

Goal 1: To determine the participants' level of understanding of church teachings and pastoral practices in the area of ministry to persons with disabilities.

<sup>140</sup> The original survey team was composed of three hundred and seventeen individuals. One hundred and twenty-seven of them did not respond to the Post-Survey. It is sufficient to state that the overall demographics of the team did not change and that no one expressed negative reasons for not responding. Possible reasons for this decline will be discussed in Chapter 5. See Appendix M for a comparison of the demographics of the participant questionnaire with the demographics of the Post-Survey.

<sup>&</sup>lt;sup>141</sup> See Appendix H.3 for a copy of the Post-Survey.

The Pre-Survey measured participants' knowledge of church teachings. The Post-Survey would measure increased knowledge or appreciation due to the website (Statement 4).

Goal 2: To provide information that would assist persons with disabilities, families, priests and pastoral ministers, etc. to further enhance an understanding of the church's acceptance of persons with disabilities into the life of the church.

The author measured this by requesting the participants to respond to the following three statements on the Post-Survey. The statements were: "I think that the website assists people in better understanding the Church's teachings regarding persons with disabilities" (Statement 6), "This website is of value to me" (Statement 7), and "I plan to visit this website as a source of information in the future" (Statement 8).

Goal 3: To provide an interactive medium that could adapt to new questions and needs.

Interactivity is a unique feature of a web-based medium. To measure this feature, participants would respond to "This website was easy to use" (Statement 1), "I found the material on this website easy to read and understand" (Statement 2), "I was able to find the information I was interested in or searching for" (Statement 3), and "I feel that my suggestions and input helped shape the information contained on this website" (Statement 5).

The results are presented here as they *relate* to the three goals of the Post-Survey, and not sequentially as they *appear* in the Post-Survey. The author will first consider the overall responses, and then compare the subgroup responses. The subgroup responses will be presented as part of the evaluation of each goal and not as a separate section, as was done in the Pre-Survey, above. Analyzed in this manner, it will be easier to determine success or failure of each goal.

#### Statistical Results

The overall responses showed far less variation than the Pre-Survey had demonstrated. In most categories the consensus was more positive, with few negative responses. A visual overview of the responses to the eight statements can be found in Table 8.<sup>142</sup>

Statement Responses Strongly Agree 105 56% 105 56% 39% 41% 28% 103 74 54% 45% 48% 39% Agree 73 73 39% 89 47% 81 43% 71 38% 77 41% 81 43% 39% Neither Agree or Disagree 9 5% 20 11% 29 15% 57 31% 5% 9% 18 11% Disagree 1 1% ŀ 1% 2% 3 2% 5 3% 4 I 1% 4 2% 2% Strongly Disagree 0 0% 1% 1% 0% 0 1% 0% 1% 1% Grand Total 188 189 188 190 185 190 190 189

Table 9. Total Responses to the Eight Statements of the Post-Survey

#### **Evaluation of Goal One**

The first goal is "to determine the participants' level of understanding of church teachings and pastoral practices in the area of ministry to persons with disabilities." To determine the website's impact on the participant's understanding, the author asked the participants to respond to "My appreciation of Church's teachings and pastoral practices in the area of ministry to persons with disabilities has increased due to this website" (Statement 4). Eighty-four percent of the respondents "agreed" or "strongly agreed" that the website has impacted their appreciation of church teachings. Fifteen percent neither agreed nor disagreed with the statement, while only two percent disagreed. Considering that many had stated that they were familiar with the church's teaching on persons with

 $<sup>^{142}</sup>$  To view the responses by subgroups to the eight statements of the Post-Survey, see Appendix N.

disabilities in the Pre-Survey, this is a remarkable result. 143

The subgroups demonstrated consistently positive responses as well. It is noteworthy to point out that eighty-four percent of the persons from other religious traditions "strongly agreed" or "agreed" with Statement 4. Other groups, such as parents of a person with a disability (89%), deacons (100%), religious brothers (100%), others (85%), and priests (79%) "agreed" or "strongly agreed" with the statement. All of these groups had one thing in common. None of them had a single "disagree" or "strongly disagree" response to Statement 4. In fact, there were no subgroups that had a "strongly disagree" response to this statement.

The "disagree" response came from advocates (1%), pastoral ministers (7%), religious sisters (8%), volunteers (3%), professionals in the field of disability (2%), relatives of a person with a disability (2%), and persons with a disability (5%). 144

#### Evaluation of Goal Two

The second goal of the Post-Survey was to determine if the website provided "information that would assist persons with disabilities, families, priests and pastoral ministers, etc. to further enhance an understanding of the church's acceptance of persons with disabilities into the life of the church." Statements 6, 7, and 8 would measure whether the participants thought that the website provides information that assists in the

late the pre-Survey forty-five percent had "strongly agreed" or "agreed" that they... "feel familiar with church teachings regarding persons with disabilities." Thirty-seven percent had "strongly agreed" or "agreed" that if "asked advice on a specific question regarding the place of persons with disabilities in the church (they) would feel confident to know where to find the church's position."

Those who make up this last group require a special word since the website is ultimately for them. The five percent of persons with disabilities who responded "disagree" to Statement 4 was actually one person. This person explained in his survey that, due to his cognitive disability and lack of computer skills, he had difficulty navigating the website and found it frustrating. On the other hand, ninety percent of other persons with a disability stated that the website enhanced their appreciation of church teachings.

integration of persons with disabilities into the church.

Participants first responded to the statement, "I think that the website assists people in better understanding the Church's teachings regarding persons with disabilities" (Statement 6). The responses were very positive. Ninety-five percent "agreed" or "strongly agreed" with the statement. Only five percent "neither agreed nor disagreed," and one percent "disagreed." This one percent represented one person.

On Statement 7, "The website is of value to me," the survey team was positive, but less so than with Statement 6. Eighty-eight percent "agreed" or "strongly agreed" with the statement. Nine percent "neither agreed nor disagreed" and three percent either "disagreed" (2%) or "strongly disagreed" (1%).

Finally, Statement 8, "I plan to visit this website as a source of information in the future," was suggested by the focus group as a way to determine if the participant valued it enough to consider the website an on-going source of information. The responses were consistent with Statement 7 and matched the responses regarding the personal value of the site. Eighty-seven percent "agreed" or "strongly agreed" that they would again visit the site. Eleven percent were unsure ("neither agree nor disagree"), and three percent responded "disagree" or "strongly disagree." The overall results for Statements 6, 7 and 8 indicate very strong support of the website as a viable medium of information.

The subgroups were fairly consistent with their responses to Statement 4 (Goal 1) in the previous section. The most positive responses to Statement 6 ("I think that the website assists people in better understanding the Church's teachings regarding persons with disabilities") came from nearly all subgroups. Advocates (96%), deacons (100%), other religious traditions (100%), pastoral ministers (93%), person with a disability

(95%), priests (100%), professionals (94%), relative of a person with a disability (92%), religious brothers (100%), religious sisters (93%), volunteers (96%), and others (100%) either "agree" or "strongly agree" with the statement. Not one of these groups responded "disagree" or "strongly disagree."

A parent of a person with a disability was the only one in the subgroup to respond negatively to Statement 6. Eighty-nine percent "agreed or "strongly agreed," while one person (2%) disagreed. It is not possible to determine why the individual did not feel that the website "assists people to better understand the church's teachings." It is interesting that this same person "strongly agreed" with Statement 7, "this website is of value to me."

The responses from the subgroups to Statement 7, "this website is of value to me" were consistent to Statement 6. Every group responded positively eoneerning the value of the website. The negative responses ("disagree") eame from diverse sources.

Advocates (1%), pastoral ministers (7%), person with a disability (1%), relative of a person with a disability (1%), religious sister (8%), volunteer (3%) and professionals ("disagree" [2%] or "strongly disagree" [1%]) expressed negative responses to the personal value of the website.

It is notable that one person from the professional subgroup responded "strongly disagrec" to Statement 7. Different from the other responses, most people here gave reasons for their disagreement to Statement 7 in the open-ended section of the Post-Survey. With the exception of the professionals, the other groups responded negatively because they indicated that they did not feel that the website provided enough information on local opportunities such as the location of accessible churches in the

Catholic Diocese of Cleveland. The professionals who responded negatively stated that the website was not pertinent to their jobs or their interests. The website was dedicated to an arena that held no interest for them.

The author could have combined Statements 7 and 8. Statement 8, "I plan to visit this website as a source of information in the future" is a personal value judgment, as is Statement 7, "this website is of value to me." As a result, the responses of the subgroups were almost identical to both statements. Again, Statement 8 negative responses paralleled Statement 7 except in a few instances. All parents of a person with a disability saw the website as a value (Statement 7). At the same time, five percent responded that they would not visit the website ("disagreed"). The relatives of a person with a disability responded just the opposite. Two percent responded that the site is not a value (Statement 7) but none responded negatively to visiting the website in the future. The most interesting responses were from the professionals who had responded that the site was not a value (2%). On Statement 8 the same people indicated that they would visit the website in the future. It is difficult to draw a conclusion to these figures. The responses of all these individuals seem to contradict themselves. On the one hand, they see the site as a value, but on the other, they do not. No comments were submitted on the Post-Survey to illuminate this shift of opinion.

#### **Evaluation of Goal Three**

The final goal of the Post-Survey was to determine if the website and its author provided "...an interactive medium that could adapt to new questions and needs." Statements 1, 2, 3 and 5 were the statements that would elicit this information.

Statement 1, "This website was easy to use" and Statement 2, "I found the material on this website easy to read and understand" will be considered together since the overall results were almost identical. Ninety-five percent of the respondents found the website easy to use (Statement 1). Similarly, ninety-five percent responded that the material was easy to read and understand (Statement 2). There was little ambivalence in their answers. Only five percent (nine people) responded "neither agree nor disagree." Negative statements were few. One person (1%) "disagreed" with Statement 1, while only two people "disagreed" (1%) or "strongly disagreed" (1%) with Statement 2.

The subgroups indicated little variance from the overall results. Only one parent of a person with a disability (1%) indicated difficulty in using the website (Statement 1). On Statement 2, the same parent "strongly disagreed" that the "...material on this website is easy to read and understand." One pastoral minister (7%), one religious sister (8%), and one person with a disability (5%)<sup>145</sup> also found the material difficult to read and understand. Overall, each subgroup indicated that the website was consistent in its ease of accessibility and its readability. This result is surprising, when one considers the various academic backgrounds of the participants. In general, no one commented that the material was either simplistic or too lofty for the average visitor or the scholar. In fact, some of the most positive feedback came from the persons with Ph.D.'s who participated.

Statement 1 and 2 dealt with the fundamentals of the website, ease of access, and readability. Statement 3, "I was able to find the information I was interested in or searching for" asks whether the website provided information the participant was interested in learning. This question intended to probe another level of interactivity.

This person with a disability is the same person mentioned previously. He expressed that his cognitive disabilities and lack of computer skills made the website difficult to utilize.

After providing their opinions in the Pre-Survey, would the team members see them reflected on the website?

Results were somewhat mixed in response to this statement. Overall, eighty-six percent "agree" or "strongly agree" that the website provided what they were looking for. Eleven percent of the respondents "neither agree nor disagree" with the statement. Many of these had not initially expressed specific suggestions for the site. Therefore, in many cases, they had no expectations upon visiting. Two percent of the survey team reported that they "disagree" and one percent "strongly disagree" with the statement. These five individuals did not find what they were looking for.

The subgroups demonstrated slight variations of opinion on Statement 3. The most positive responses were from priests, religious brothers, and deacons. These groups answered "agree" or "strongly agree" one hundred percent. This response is not surprising. The Pre-Survey had indicated that priests especially were concerned with single issues such as sacramental preparation and liturgical adaptations. These issues were presented on the website almost immediately since these were part of Chapter 2 and were prepared in advance of the Pre-Survey results.

The most negative responses came from advocates (1% "disagree" and 1% "strongly disagree"), parents of a person with a disability (5% "disagree" and 2% "strongly disagree"), pastoral ministers (7% "disagree"), persons with a disability (5% "disagree" and 5% "strongly disagree"), relatives of a person with a disability (2% "disagree" and 2% "strongly disagree"), religious sister (8% "disagree"), and volunteers (3% "disagree"). These were individuals who indicated that the subjects they were interested in were not present. The vast majority of those subjects had been mentioned

previously and generally involved specific opportunities in the Catholic Diocese of Cleveland for persons with disabilities. Often the subject matter was specific to individuals in their lives and fell outside of the vision and scope of this website. As indicated by previous responses, the lack of information on their personal interest areas did not deter most of these people from seeing a value to the website. Many expressed hopes for future website development and plan to continue to visit the site.

The final statement to measure whether the project had created an interactive medium was the fifth one, "I feel that my suggestions and input helped shape the information contained on this website." This question is important to determine if the participants felt that the author was not only listening to them, but also developing the website based on their input.

The overall results were more mixed than any other statement responses. The responses indicated an uncertainty as to whether they helped shape the website. Sixty-six percent said "agree" or "strongly agree" with Statement 5. Thirty-one percent responded "neither agree nor disagree." This response indicates an uncertainty as to whether their input had anything to do with the material on the site or its development. Another four percent said "disagree" (3%) or "strongly disagree" (1%). Though the majority was very positive, the larger interest here is in those who were unsure if their input was utilized.

The subgroup responses indicate that the percentage of those who voiced uncertainty ("neither agree nor disagree") was fairly consistent for all groups. Each group expressed this ambivalent response from at least twenty percent of their members. The highest uncertain response came from the "other" subgroup (77%). This result was followed by deacons (50%), pastoral ministers (40%), religious sisters (38%), and priests

(33%). Between twenty and thirty percent of all other groups responded "uncertain" to Statement 5.

The uncertain responses to Statement 5 were due to one of three general reasons unrelated to any one subgroup. Some expressed that they had not visited the website as frequently as they had intended. As a result, they did not submit any suggestions for the site. Others wished to watch the development of the site and did not desire to submit any suggestions. A third group did submit suggestions, but did not see them immediately employed on the website. These individuals felt that their input had no value to the site. Some of these people stated that they understood that the project was to last a short time, and that they should not have expected everything to be accomplished immediately. These individuals could not respond that their input had helped to construct the website.

Before presenting a conclusion, the Post-Survey presented two questions that the author will consider briefly. The first of these was suggested by the focus group. One asked, "Which area(s) of the website was most helpful/informative to you?" The focus group believed that this query would help determine what areas people felt assisted them. The respondents could submit more than one area of interest. <sup>146</sup> Eighty-one percent (153 individuals) of the total respondents completed this section. A total of four hundred and seventy-three selections were submitted. The choices were surprisingly consistent among groups. Overall, one hundred and cleven chose the "Resources/Links" page as most helpful. It was the top choice of parents, priests, professionals, relatives, pastoral ministers, and those from other religious traditions.

<sup>146</sup> Considering the many pages that composed the website, this question could be difficult to calculate. The author chose to group them into the sections listed on the website's link buttons.

The next most popular area was "Church Teachings." Ninety-six respondents chose this area. It was the most frequent choice of advocates, volunteers, religious brothers, and persons with a disability. The third most popular section of the website, with sixty-three votes, was the "Inspirations" section. Only the professionals picked this as their first choice.

The most surprising response came from twenty-four individuals from various subgroups. Each listed a choice that was not an area on the website. They stated that what helped them the most was "just knowing that the website was there." What inspired them was not the content of the site, but realizing that the church cares. The website, to them, was a sign of welcome. See table nine for the overall choices.<sup>147</sup>

Table 10. Most Helpful/Informative Areas of the Website

Selected Areas	Total
Home Page	22
Search	3
News	5
Feedback	1
Who We Are	12
Church Teachings	96
Canon Law	14
US Bishops	7
Sacramental	7
Practical Suggestions	72
Disability Etiquette	12
Definitions	10
People 1 <sup>st</sup> Language	4
Inspirations	63
Resources/Links	111
Attitudes & Causes	4
Social Justice	6
That the Website is there!	24

Question C of the Post-Survey asked if the participant had any other comments on this project. Sixty-nine percent responded (131 people). The comments were divided

<sup>&</sup>lt;sup>147</sup> See Appendix O for the subgroup's choices of favorite website pages.

into three groups. The vast majority simply congratulated the author on the creation of the website or extolled its merits. The next group suggested topics for the website, such as the location of accessible churches. These responses were repetitive comments made throughout the project. The last individuals used the space to apologize for not participating as they had originally intended. The comments from the subgroups were consistent with the overall responses.

Finally, a short question in a yes-or-no format was included in the survey. The author asked the team members if they would like to receive follow-up notices when the website was updated. This question was included to confirm ongoing interest. A majority, eighty-five percent (158 people), requested notification on updates to the website. Several of those who declined stated that "knowing that the website is there is all they need." This endorsement confirmed the expressed approval of the website. <sup>148</sup>

#### Part 4: Conclusion

This project had several measurable objectives to determine success or failure.

Overall, the author wished to test the theory that the use of an internet website would be a useful medium to promulgate church teachings and practical suggestions. In other words, would the internet constitute a new area of ministry to assist the integration of persons with disabilities into the church? From the qualitative data received in the Post-Survey, it is clear that the participants felt that the website was a value. Moreover, the vast majority (88%) reported that the site was a value to them personally. They also indicated that the website was a good method of providing information to further integrate persons with

<sup>&</sup>lt;sup>148</sup> This group will form the basis of a group to be sent email updates. The author will post an opportunity to join the group on the website. People will be able to enroll online and to cancel their participation at any time. This practice will continue to create an interactive website.

disabilities into the church (95%).

On the other hand, it must be said that the website was not a success for every participant. One hundred and twenty-seven people failed to return their Post-Surveys.

The reasons will be discussed in Chapter 5. In this group were individuals who found the use of a website to be too difficult of a medium. It can be concluded that the use of this medium is a valuable form of ministry, but only valuable to a portion of the community. A website should be utilized in conjunction with other modes of communication currently used by the church to convey teachings and pastoral suggestions.

In addition to the overall goal, this project intended to achieve four measurable sub-goals. These four measurable goals were the means to overall end. They were:

- 1. To determine the participants' level of understanding of church teachings and pastoral practices in the area of ministry to persons with disabilities.
- 2. To determine the type of information that a theological and pastoral website should provide.
- 3. To provide information that would assist persons with disabilities, families, priests and pastoral ministers, etc. to further enhance an understanding of the church's acceptance of persons with disabilities into the life of the church.
- 4. To provide an interactive medium that could adapt to new questions and needs.

The Pre-Survey successfully achieved Goals 1 and 2. It uncovered the participant's level of understanding church teaching, but it did so in a way that was able to compare the subcategories of participants. This result enabled the author to make conclusions on the viewpoint of one group versus another for example, priests and parents. The Pre-Survey was able to determine the type of information that the participant felt was useful (Goal 2). The subgroups' results were especially helpful in determining this outcome. The added benefit of an interactive website was that the subgroups' continued interest in particular subjects was monitored during the trial period.

Goals 3 and 4 were successfully accomplished as shown by the Post-Survey. The survey team determined overwhelmingly that the website provided helpful information (Goal 3). There was an appreciation of what was presented and an expressed anticipation of the future development of the site. The surprise was that the website itself constituted a sign of hope. Its very existence assisted in realizing that the church truly cares about the integration of persons with disabilities into its community.

The last goal, "To provide an interactive medium that could adapt to new questions and needs," was validated in two ways. The Post-Survey expressed an overall belief that the participants felt that they contributed to the site's development (66%). More than this belief, the emails that were received during the course of the trial period (June to October, 2006) showed an interactive element that was not measured by the Post-Survey. Over three hundred emails were received during this period. Many asked for additions to the website or posed personal questions that related specifically to their lives. The website functions as a door to someone whom the person can contact. This result is the real goal of making a website interactive. The website has its limitations on what it can present. When there is a person who can be contacted with personal issues, and the inquirer knows that there will be a response, the website becomes interactive in a ministerial way.

In the cnd, the website is one more method that the church can use to reach out to a marginalized population. It is as valuable and as unique as printed material, books, videos, and personal presentations. Each has limitations as well as value. Each has a place in ministry. There is a growing population of people who find the internet useful for their daily lives. They access it to shop, gather information, and to socialize. Many of

the participants, particularly the parents, stated that they had used the internet to learn information about their loved ones' disabilities. One of the greatest successes of this project is that *Catholicdisabilityteachings.com* adds a church presence to the dialogue taking place in cyber-space. This presence creates a new ministerial platform and adds a new vehicle to promote the integration of person with disabilities into the church community.

#### CHAPTER 5

#### REFLECTIONS AND CONCLUSIONS

"A *Different* Journey." The title of this work has many meanings. The life journey of the person with disabilities is different from that of the typical person. The desire of these individuals to participate in the life of the church fully is similar to that of the typical person, but it is different because of life experiences. This work has been a different journey for the author, as well. The project investigated a new ministerial medium, which led to a different approach to communicating and presenting pastoral suggestions and church teachings. In the process the author continually reflected on many aspects of current pastoral practices.

This chapter presents personal reflections on the project and the meanings derived. It presents conclusions and suggestions for an ongoing ministry to persons with disabilities. The chapter has three parts. The first section will reflect on the website as a ministerial tool. Here, the author will continue to discuss the success or failure of the project. He will examine the goals considered in Chapter 4, but will also consider feedback from persons who visited the website but were not part of the survey team.

Next, the author presents what he learned in the process. Was there new information or was there anything that was a surprise? In the last section, the author posits a few suggestions for the continuing ministry to persons with disabilities. These suggestions target website ministry, the Catholic Diocese of Cleveland, and the church in the United States. These reflections do not encompass all that has been gained from this project.

The author has learned and continues to learn more from this ministry. It will take years to reflect and to apply the findings. A website ministry is an evolving outreach. It will continue to transform as new needs are presented. As a ministry, it is a *different* journey.

#### Can a Website Be a Valid Approach to Pastoral Ministry?

As a tool to reach out to people, a website offers a new medium that can present theological and/or pastoral information, and at the same time, provide an interactive means for an individual to communicate personal challenges, needs, and stories. The results of the surveys presented in Chapter 4 soundly endorse this tool as a valid pastoral method. In addition to those on the survey team, there were others who visited the site and made comments. By the end of 2006 over three thousand people had visited the website (more than 400 people per month). The project ended in October 2006, but people continued to visit. During the time of the project (June to October 2006), many members of the survey team admitted that they did not visit the site as frequently as they had wished. Considering the emails that arrived from those not on the survey team, the author concludes that there were many more who visited the site than were part of the survey project. What were their reactions?

All the visitors to the website showed enthusiasm and support of the vision of the ministry. Those who were not part of the survey team showed an even greater enthusiasm. They sent emails from various parts of the United States, and depending on what was available to them locally, expressed a desire for such ministries in their own dioceses. Before they visited the website, several people felt that no organized ministry existed in their area, and that they had thought that the church did not care about persons with disabilities. Several expressed joy in very emotional terms because this information

and the ability to speak to someone existed. Others wanted to discuss forming ministries to persons with disabilities. One person in Pennsylvania stated that she and others had presented the website to their bishop, who endorsed the development of such a ministry in their diocese. Two people drove from neighboring states to meet with the author and discuss possibilities.

One national organization which had previously stated that time and money deterred them from creating a similar website contacted the author in June 2006 and requested a phone conference. The chairperson of their board, the executive director and the author discussed the project in detail. At the conclusion, the executive director stated that this group would be developing a national website in order to present much of the same information. This unforeseen result will be discussed below in the "Next Steps" section of this chapter. For now, it is sufficient to state that this decision was a great compliment to this project. In summary, the endorsement of those who were not on the survey team was stronger than any comments received locally. It is obvious that the majority of the people who visited saw this site as an exciting new ministry.

In the introduction, the author had asked several questions to determine the success of the website. Two questions went beyond what could be measured by responses to surveys or comments. Would the website be a value to people in the context of their lives? Would it assist one person to access church? The importance cannot be measured by simple comments. Even when people posed personal questions, the author could seldom determine what happened to the information. There was one exception. In September 2006 a woman emailed that after reviewing information on the website and discussing her issue with the author, she had decided to approach her church with a

request. She stated that she had changed her thinking about the reception of the Eucharist. She now believed that her fourteen year old daughter who has autism could receive the Sacrament. When she emailed that her daughter was being prepared and would be receiving Eucharist soon, the author found the answer to his question, "Would it assist one person to access church?"

In addition, during the project and continuing until now, the author received invitations to attend two special liturgical celebrations for persons with disabilities that took place in the Catholic Diocese of Cleveland. These were orchestrated by parents who approached their pastors with integration information received from the website. Ecumenically, the author has met and/or discussed ministry to persons with disabilities from three other religious congregations. This dialogue continues and may result in cooperative ministries in the future. In summary, the author is convinced more than ever that a website is a valid ministerial tool and adds to the body of pastoral practices. It is one more way for the church to reach out to contemporary society. It also is a platform that may enhances ecumenical dialogue.

#### What Was Learned?

The author had such varied experiences during this project that it is impossible to state all of them here. As previously noted, it will take years to fully understand the ramifications of this experiment. As a result, for this section, he will state a few of the lessons learned.

One of the greatest surprises was the enthusiasm of the participants. No matter how they described themselves (priest, parent or person with a disability), one common element was a genuine interest in the development of the website. From the focus group,

to the survey team, to the casual visitor, the author was overwhelmed at times with the passion people displayed. Reflecting on this, it appears that their enthusiasm signified more than just an interest in the website. Their fervor was a desire to know that the church *cares*. The website merely represented this desire. It somehow expressed what many people were looking for.

Along with this benefit, people expressed that the website was a sign of hope. The author had not expected this result. He had begun the project with a concern for the content to be presented. After a few months he realized that the content was secondary. What people were looking for was a hope that the church would care. The church has expressed its beliefs about persons with disabilities for years. What the website did was to present this hope in a medium that the visitor had been using to look for information. The site simply took the church's teachings and pastoral suggestions to the marketplace where people were already shopping. The greatest compliment the author received was from those who stated that *Catholicdisabiltyteachings.com* brought hope to their life. If there was a cathartic moment, it would have been at the points when people emailed that the website had changed their thinking and their views of the church. Giving hope is a daily goal of all ministries. Having people see hope in this website underscores its ministerial value.

Another important item that was learned has pastoral implications. As stated in Chapter 4, the author learned that "integration" meant different things to different people. As noted, the most obvious differences were between parents and priests. Parents tended to think globally in terms of the person's entire life. Priests tended to think liturgically or sacramentally. Going beyond these two groups, the construction of the website indicated

that various groups valued different information to promote integration. Others, primarily advocates, were opposed to information such as definitions of disabilities. The differences were numerous. If the reader had returned to Chapter 4 and re-examined the pages on what people valued on the website, it would be obvious that the priorities vary. How does the church achieve the integration of persons with disabilities into the church if "integration" is understood differently by diverse groups? This is a pastoral issue that will be discussed in the third section below.

One question that remains open from Chapter 4 is why did one hundred and twenty-seven people not respond to the Post-Survey? Had they dropped out of the project? Were they no longer interested? Was the website not what they were looking for? The author was surprised by this number. To answer these questions, the author emailed a short questionnaire to the members of the survey team who had not responded to the Post-Survey. To accomplish this quickly, he created a Follow-Up Survey that was sent to sixty-one people. The author chose individuals who had email addresses and had completed the pre-survey. Of the responses received (56%), no negative responses to the project were indicated. The majority requested notifications of future updates to the website. 149

After reviewing the responses to the Follow-Up Survey, the author concluded that, no matter what reason was given, the time commitment required of the participants played a part. The author tried to build a website that would speak to priorities and yet was interesting enough to hold interest. What he did not consider was that the time line for the project (June to October) may have been too long. It appears that the attention of

<sup>&</sup>lt;sup>149</sup> This Follow-Up Survey was not part of the project, and so was not included in Chapter 4. See Appendix P for a sample of the email survey sent to participants who did not respond to the Post-Survey and the results of the survey.

some of the survey team was lost. If others decide to follow the methodology of this project, the author suggests that they follow a shorter time for the evaluation of the website. All the results could have been gathered after two months. The comments after that were redundant and added no new information. With a shorter trial period, there is a greater chance that attention of the participants will not wander to other matters. The author feels that this point is perhaps the greatest flaw of this project.

Lastly, the author learned how much work a project like this entails. This may seem like a small point, but it is important. As mentioned in a previous chapter, a person who is considering the construction of a website and evaluating it using a similar methodology should consider the amount of work he or she is about to undertake. This being said, the author would not have changed the majority of his methodology. The real learning came from being totally immersed in this project. Most valuably, the website became interactive and encouraged people to communicate. Even though the author cautions the reader who may want to follow the same trail, the benefits of the task far outweigh the work involved.

#### **Next Steps**

Now that the project is finished, what "next steps" can be suggested? The author divides this section among the website *per se*, the role of the Catholic Diocese of Cleveland, other dioceses, and the church in the United States. Each of these will play a part if the integration of persons with disabilities is to continue as a viable ministry.

As far as the website, *Catholicdisabilityteachings.com*, the author realizes that the site is far from finished. In fact, he expects that the site will never be finished. It is designed to evolve and to change with new needs that are presented. There are sections

such as "Sacraments" and "Social Justice" that still have to be written. More than the need to fill in information, the author must make the website accessible to persons with disabilities. This is one technical area that is lacking. The author has not acquired the skills. His plan is to seek the advice of an expert in this area and either attain the needed information or hire a company to redesign the website in order to make it accessible.

The other goal for the website is to continue to promote it. Many visitors to the site wrote that the information needed to get to the typical parish member. An exact plan for this publicizing has not been designed at the present. There are diocesan publications that can assist in getting information to priests. These publications will be one aspect that the author will employ. It is hoped that the website can be used eventually as a common pastoral tool in the Catholic Diocese of Cleveland.

If someone were to take what has been accomplished in this project so far and advance it, what areas of study are needed? The possibilities are limitless. Websites can expand a subject simply by creating yet another new site and linking it to the original. When it comes to subject matter, the author suggests that websites for specific disability groups could be pastorally beneficial. For example, if someone were interested in ministry to persons who are deaf, a website dedicated to this specific area would advance this area of ministry. *Catholicdisabilityteachings.com* is a general site and serves well in providing teachings and suggestions that pertain to all persons with disabilities. Persons who fit a specific disability category (blind, deaf or cognitive disability for example) often have concerns and questions specific to their experiences. Having more specific websites that pertain to certain disabilities would greatly enhance the pastoral use of the internet. The websites could form a network of ministries working together.

Going a step further toward a more universal design, the author believes that a website plan should be developed on the national as well as the diocesan level. After discussing this issue with a national office, he is convinced that much of the material on Catholic disability teachings.com should be on a national website. This website could mimic the design of the present site, but it could serve as a hub of information. Anyone in the United States would be able to access the basic teachings and pastoral suggestions of the church. In addition, links could be available to connect the visitor to a website in his or her own diocese. In this way, the local websites could deal with local issues and present information specific to that diocese. The author realizes that not every diocese will create such a local website. The reality is that many dioceses do not have an active ministry for persons with disabilities. <sup>150</sup> The author believes that, even if all dioceses are not represented with websites, those that are will present examples of ministry that could be employed by others. This could result in a dialogue among different dioceses. As it happened in this project, this internet presence could enhance an ecumenical dialogue, as well.

The Catholic Diocese of Cleveland could play a major role in this development of ministry. It already possesses an existing website that presents the ministrics and services to persons with disabilities currently available. With the addition of Catholic disability teachings. com the Diocese can serve as a model for others. This Diocese has been blessed with many active ministries and services to persons with

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<sup>150</sup> The author is not suggesting that every diocese should set up a separate office of ministry for persons with disabilities. The situation in each diocese is different and there are different models that can be utilized. Still, some form of ministry is called for. See Appendix Q for some suggested diocesan models of ministry to persons with disabilities.

<sup>&</sup>lt;sup>151</sup> This website is available from http://www.clevelandcatholiccharities.org/disability.

disabilities for many years, but there is always more that could be done. Speaking just in terms of the website ministry, the author feels that this project has uncovered requests that the Catholic Diocese of Cleveland could respond to with ease.

Catholic disability teachings.com currently presents teachings and suggested practices. What people are requesting is information that can enhance their own integration. For example, there are many requests for the location of accessible churches. Even more, they want to know what type of accessibility is available (Sign language, ramps, TTY's, audio cnhancement, etc.). A website would be an ideal setting for presenting such information, since it can change rapidly. Another request is to find out where ministries and parish programs are occurring for persons with disabilities. The diocesan website could support this request. People are requesting more than information. They are asking for details on parish communities so that they can personally access a church that provides a welcoming community.

There is one final area involving teaching and research that should be considered as a goal. When one considers that the *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities* was issued in 1978, it is surprising how little progress has occurred. During the project, the author was surprised by the lack of awareness of this document among religious leaders. The pastoral statement made specific recommendations that have not been applied by every diocese. This result is not surprising if the leaders have not been supplied with the needed information. For example, the Bishops called for the integration of persons with disabilities into the full participation in the Christian community. They called for a ministry that is carried out "with" persons with disabilities and not just a ministry provided "for" them.

[The document calls for parishes] to prepare for the integration of persons with disabilities by creating an attitude of "welcome," an attitude based on knowledge, careful reflection and prayer. Since physical access is a sign of welcome, physical modifications of the facility should be considered as well as attitudinal modification. Mere cost must never be the exclusive consideration, however, since the provisions of free access to religious functions for all interested people is a pastoral duty. <sup>152</sup>

The Bishops also address the ministerial role that persons with disabilities can play in the church community once access is accomplished.

[The Bishops] look forward to the day when more individuals with disabilities are active in the full-time, professional service of the Church, and we applaud recent decisions to accept qualified candidates for ordination or the religious life in spite of their significant disabilities. <sup>153</sup>

The author presents these statements to point out the need for educational and pastoral training in the area of ministry to persons with disabilities. This pastoral ministry needs much more research and application. Centers of training for priests and pastoral ministers must not consider disability ministry courses as separate from the routine training provided. When one considers the presence of persons with disabilities in society (20%), training to minister to persons with disabilities should be considered a routine component of any pastoral development.

This conclusion brings us back to one point discussed in the first section of this chapter. The author stated that he was surprised that the meaning of "integration" differed among various groups. This difference was especially true between priests and parents. Again, when one considers the lack of training offered in this ministry, this result is not surprising. Training in this area will not just enhance an individual's professional development; it will also provide a means of understanding the needs and

<sup>&</sup>lt;sup>152</sup> United States Conference of Catholic Bishops, *Pastoral Statement of U.S. Catholic Bishops on People with Disabilities, Article* 21.

<sup>153</sup> Ibid., Article 24.

wishes of other groups. In addition to formal training, or perhaps as part of it, a common understanding of the meaning of integration is necessary. The author feels that the church must commit itself to a plan to fully integrate persons with disabilities as the Bishops directed in 1978. One of the first steps is developing an understanding of what "integration" means. Pastoral leaders can then develop the ability to accomplish the task in their own parishes. This ministry is not a *voluntary* one. It is essential to the calling of all priests and pastoral leaders.

"A Different Journey." It is similar to everyonc else's, but different because of the uniqueness of the individual. It is important to keep in mind that as we continue to integrate those who are different into our church community, we must appreciate both the similarities they share and the unique gifts that they bring. It is in listening to the person, understanding his or her needs, and in appreciating those unique gifts that the church will continue to minister to all the people of God, a people called to be part of the evolving and expanding Body of Christ on earth.

We look to the future with what we feel is a realistic optimism. The Church has a tradition of ministry to people with disabilities, and this tradition will fuel the stronger, more broadly based efforts called for by contemporary circumstances. We also have faith that our quest for justice, increasingly enlisted on the side of individuals with disabilities, will work powerfully in their behalf. No one would deny that every man, woman and child has the right to develop his or her potential to the fullest. With God's help and our own determination, the day will come when that right is realized in the lives of all people with disabilities. <sup>154</sup>

154 Ibid., Article 35.

# APPENDIX A

# TEN PRINCIPLES OF SOCIAL JUSTICE AND AN EXAMPLE OF THEIR USE IN CONTEMPORARY PASTORAL STATEMENTS

# Ten Social Justice Principles Definitions Contemporary Pastoral Statements that Reflect these Principles

#### 1) Dignity of the Human Person

All people are sacred, made in the image and likeness of God. People do not lose dignity because of disability, poverty, age, lack of success, or race. This emphasizes people over things, being over having. This principle is the foundation for the Church's promotion of respect for human life. <sup>155</sup>

There is a growing awareness of the sublime dignity of human persons, who stand above all things and whose rights and duties are universal and inviolable. They ought, therefore, to have ready access to all that is necessary for living a genuinely human life: for example, food, clothing, housing ... the right to education, and work... 156

#### 2) Common Good and Community

The human person is both sacred and social. We realize our dignity and rights in relationship with others, in community. Human beings grow and achieve fulfillment in community. All people have a right and a duty to participate in society, seeking together the common good and well-being of all. The family is a central social institution that must be supported and strengthened. 157

The members of the Church, as members of society, have the same right and duty to promote the common good as do other citizens. Christians ought to fulfill their temporal obligations with fidelity and competence. They should act as a leaven in the world, in their family, professional, social, cultural and political life. 158

#### 3) Rights and Responsibilities

Pcople have a fundamental right to life, food, shelter, health carc, education and employment. All people have a right to participate in decisions that affect their lives. Corresponding to these rights are duties and responsibilities. For example,

<sup>&</sup>lt;sup>155</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice (St Paul, MN. ND, accessed January 25, 2006); Available from http://www.osjspm.org/cst/pdf/cstprinciples--osj.pdf; Internet.

Second Vatican Council, "Gaudium et Spes," #26, Pastoral Constitution on the Church in the Modern World (1965 accessed January 25, 2006); Available from http://www.osjspm.org/cst/q\_dignity.htm); Internet.

<sup>&</sup>lt;sup>157</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

World Synod of Catholic Bishops, *Justice in the World* # 38 (1971, accessed January 25, 2006); Available at http://www.osjspm.org/cst/jw.htm; Internet.

all persons have a duty to respect the rights of others in society. All persons have a responsibility to participate in social and political activities and institutions that promote the common good.<sup>159</sup>

It is agreed that in our time the common good is chiefly guaranteed when personal rights and duties are maintained. The chief concern of civil authorities must therefore be to ensure that these rights are acknowledged, respected, coordinated with other rights, defended and promoted, so that in this way everyone may more easily carry out their duties. For "to safeguard the inviolable rights of the human person, and to facilitate the fulfillment of each one's duties, should be the chief duty of every public authority." <sup>160</sup>

#### 4) Option for the Poor

The moral test of a society is how it treats its most vulnerable members. The poor have the most urgent moral claim on the conscience of the nation. We are called to look at public policy decisions in terms of how they affect the poor. The "option for the poor," is not an adversarial slogan that pits one group or class against another. Rather it states that the deprivation and powerlessness of the poor wounds the whole community. <sup>161</sup>

Listening to the cry of those who suffer violence and are oppressed by unjust systems and structures, and hearing the appeal of a world that by its perversity contradicts the plan of its Creator, we have shared our awareness of the Church's vocation to be present in the heart of the world by proclaiming the Good News to the poor, freedom to the oppressed, and joy to the afflicted. 162

#### 5) Global Solidarity and Development

We are one human family. Our responsibilities to each other cross national, racial, economic and ideological differences. We are called to work globally for justice. Authentic development must be full human development. It must respect and promote personal, social, economic, and political rights, including the rights of nations and of peoples. It must avoid the extremists of underdevelopment on the one hand, and "superdevelopment" on the other. Accumulating material goods,

<sup>&</sup>lt;sup>159</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

<sup>&</sup>lt;sup>160</sup> Pope John XXIII, *Pacem in Terris* #60 (1963, accessed January 25, 2006); Available at http://www.osjspm.org/cst/pt.htm; Internet.

<sup>&</sup>lt;sup>161</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

World Synod of Catholic Bishops, *Justice in the World #5* (1971, accessed January 25, 2006); Available at http://www.osjspm.org/cst/jw.htm; Internet.

and technical resources will be unsatisfactory and debasing if there is no respect for the moral, cultural, and spiritual dimensions of the person. 163

There can be no progress towards the complete development of the human person without the simultaneous development of all humanity in the spirit of solidarity. 164

#### 6) Promotion of Peace and Disarmament

Catholic teaching understands peace as a positive, action-oriented concept. Peace is not just the absence of war. It involves mutual respect and collaboration between peoples and nations. There is a close relationship between peace and justice. Peace is the fruit of justice and is dependent upon right order among human beings and human institutions.<sup>165</sup>

It is obvious that individual countries cannot rightly seek their own interests and develop themselves in isolation from the rest, for the prosperity and development of one country follows partly in the train of the prosperity and progress of all the rest and partly produces that prosperity and progress. the follows partly produces that prosperity and progress.

### 7) Stewardship of God's Creation

The goods of the earth are gifts from God, and they are intended by God for the benefit of everyone. There is a "social mortgage" that guides our use of the world's goods, and we have a responsibility to care for these goods as stewards and trustees, not as mere consumers and users. How we treat the environment is a measure of our stewardship, a sign of our respect for the Creator. 167

God destined the earth and all it contains for all people and nations so that all created things would be shared fairly by all humankind under the guidance of justice tempered by charity. <sup>168</sup>

#### 8) Dignity of Work and the Rights of Workers

<sup>&</sup>lt;sup>163</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice: Internet.

<sup>&</sup>lt;sup>164</sup> Paul VI, *Populorum Progresio*, On the Development of Peoples #43 (1967, accessed January 25, 2006); Available at http://www.osjspm.org/cst/pp.htm; Internet,

<sup>&</sup>lt;sup>165</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

<sup>&</sup>lt;sup>166</sup> John XXIII, *Pacem in Terris*, Peace on Earth #131 (1965, accessed January 25, 2006); Available at http://www.osjspm.org/cst/pt.htm, Internet.

<sup>&</sup>lt;sup>167</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

World (1965, accessed January 25, 2006); Available at http://www.osjspm.org/cst/gs\_cos2.htm; Internet.

The economy exists to serve people, not the other way around. People have a right to productive work and fair wages. Workers have the right to safe working conditions, the right to participate in decisions that affect them in the workplace, and the right to security in case of sickness, disability, unemployment or old age. All workers have the right to form unions. In fact, unions are referred to in the teaching as an "indispensable" element in the search for social justice. 169

For when people work, they not only alter things and society, they develop themselves as well. They learn much, they cultivate their resources, they go outside of themselves and beyond themselves. Rightly understood, this kind of growth is of greater value than any external riches which can be garnered. People are more precious for what they are than for what they have. Similarly, all that people do to obtain greater justice, wider brotherhood, a more humane ordering of social relationships has greater worth than technical advances. For these advances can supply the material for human progress, but of themselves alone they can never actually bring it about. 170

# 9) Role of Government and Subsidiarity

The state has a positive moral function. It is an instrument to promote human dignity, protect human rights, and build the common good. The principle of subsidiarity holds that the functions of government should be performed at the lowest level possible, as long as they can be performed adequately. When the needs in question cannot adequately be met at the lower level, then it is not only necessary, but imperative that higher levels of government intervene. <sup>171</sup>

If any government does not acknowledge the rights of man or violates them, it not only fails in its duty, but its orders completely lack juridical force. 172

#### 10) Free Markets, Economic Initiative, and Private Property

Catholic teaching opposes collectivist and statist economic approaches. But it also rejects the notion that a free market automatically produces justice. Competition and free markets are useful elements of economic systems. However, markets must be kept within limits, because there are many needs and goods that cannot be satisfied by the market system. It is the task of the state and of all society to ensure that these needs are met. All people have a right to economic initiative and

<sup>&</sup>lt;sup>169</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

<sup>&</sup>lt;sup>170</sup> Gaudium et Spes #35; Internet.

<sup>&</sup>lt;sup>171</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

<sup>&</sup>lt;sup>172</sup> Pacem in Terris #61: Internet.

to private property, but these are not unlimited rights. No one is allowed to amass excessive wealth when others lack the basic necessities of life. 173

Individual initiative alone and the mere free play of competition could never assure successful development. One must avoid the risk of increasing still more the wealth of the rich and the dominion of the strong, whilst leaving the poor in their misery and adding to the servitude of the oppressed. 174

<sup>&</sup>lt;sup>173</sup> Archdiocese of St Paul and Minneapolis, Office of Social Justice; Internet.

<sup>&</sup>lt;sup>174</sup> Populorum Progresio #33; Internet.

# APPENDIX B

# SELECTED STATISTICS FROM THE THE NEW FREEDOM INITIATIVE

# Selected Major Findings of the New Freedom Initiative

The New Freedom Initiative 175 from President George W. Bush, reports the following general statistics:

- Fifty-Four million Americans live with disabilities, 20 percent of the U.S. population.
- Disability is not the experience of a minority of Americans. "Disability" is an experience that will touch most Americans at some point during their lives.
- Persons with disabilities are in the midst of a civil rights movement. There are many barriers to equality that face them daily. Almost half of these individuals have a severe disability, affecting their ability to see, hear, walk, or perform other basic functions of life.
- There are over 25 million family caregivers and millions more who provide aid and assistance to persons with disabilities.

The New Freedom Initiative points out that Americans with disabilities have a lower level of educational attainment than those without disabilities:

- One out of five adults with disabilities has not graduated from high school, compared to less than one of ten adults without disabilities.
- National graduation rates for students who receive special education and related services have stagnated at 27 percent for the past three years, while rates are 75 percent for students who do not rely on special education.

Americans with disabilities are poorer and more likely to be unemployed than those without disabilities:

- In 1997, over 33% of adults with disabilities lived in a household with an annual income of less than \$15,000, compared to only 12 percent of those without disabilities.
- Unemployment rates for working-age adults with disabilities have hovered at the 70
  percent level for at least the past 12 years, while rates are significantly lower for workingage adults without disabilities.

Too many Americans with disabilities remain outside the economic and social mainstream of American life:

- 71% of persons without disabilities own homes, but fewer than 10% of those with disabilities do.
- Computer usage and Internet access for persons with disabilities is half that of persons without disabilities.
- Persons with disabilities vote at a rate that is 20 percent below voters without disabilities.
   In local areas, disability issues seldom surface in election campaigns, and inaccessible polling places often discourage citizens with disabilities from voting.

<sup>&</sup>lt;sup>175</sup> George W. Bush, The *New Freedom Initiative* (2001, accessed January 16, 2006); Available at http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html; Internet.

# APPENDIX C

FINDINGS FROM THE 2000 CENSUS SURVEY

# Disability and American Families 176

#### DISABILITY PREVALENCE AMONG FAMILIES

- Census 2000 counted a total of 72.3 million families and found that nearly 28.9 percent of them (about 2 in every 7 families) reported having at least one member with a disability.
- In 13 million families, the householder had a disability (18.0 percent of all families), and in 2.8 million families (3.9 percent of all families), children had a disability.
- Disability rates varied among single-race groups and Hispanics.
- Disability was more prevalent among families in the South and in rural areas.
- One in every three families with a female householder with no husband present reported members with a disability.

#### ECONOMIC CHARACTERISTICS OF FAMILIES VARIED WITH DISABILITY STATUS

- Families with members with a disability had lower median income than other families.
- Families with members with a disability were less likely than other families to have earnings and more likely to receive income from Social Security and public assistance.
- Family householders with disabilities were less likely to be employed and less likely to be in the labor force than other family householders.
  - Among householders with disabilities, those with a mental disability had the lowest employment rate, 34.2 percent, and the largest proportion of people not in the labor force, 60.8 percent.
  - o Next were householders with a physical disability, with an employment rate of 39.3 percent in 2000, 56.8 percent of them did not participate in the labor force.
- The median income of families with a householder who worked full-time, year-round varied by whether the householder had a disability and by the type of disability.
- Families with householders with a disability were less likely to own their residence than other families.

#### DISABILITY AND FAMILY POVERTY

- In every state, families with members with a disability were more likely than other families to live in poverty.
- Of the families with two or more members with a disability, 16.5 percent were in poverty.
- Poverty and disability tended to occur in similar proportions in Black families and American Indian and Alaska Native families.
- Families in the South had higher prevalence rates of both disability and poverty.

<sup>&</sup>lt;sup>176</sup> U.S. Census Bureau, *Disability and American Families* (2005, accessed February 13, 2006); Available at http://www.census.gov/prod/2005pubs/censr-23.pdf; Internet.

# APPENDIX D

# PROJECT TIMELINE

D.1: PROPOSED PROJECT TIMELINE D.2: PROJECT TIMELINE SHOWING COMPLETION POINTS

D.1: Proposed Project Timeline

						Pro	Proposed Project Timeline A Different Journey	roject Ti	meline								
	Nov. 05	Dec. 05	Jan. 06	Feb. 06	Mar. 06	Apr. 06	May 06	June 06	July 06	Aug. 06	Sept. 06	Oct. 06	Nov. 06	Dec. 06	Jan. 07	Feb. 07	Mar. 07
Focus Grp Assembled	Î																
Theontical/Theological Section Complete							1										
Focus Grp meet				1													
Initial web site Construction				1	<u>†</u>	<u>†</u>	<u></u>										
Invite to Survey Grp					1												
Survey Grp selected (100 people)						1											
Mailing						1											
Survey Collected							1										
Analysis of survey										1							
Web site launched	:							†									
Enhancements to web site														1			
Post Survey mailed														<u>†</u>			
Survey compiled																	
Project reflection													7				1

D.2: Project Timeline Showing Completion Points

						5	A Differe	Completed Project Timeline A Different Journey	imeline y								
	Nov. 05	Dec. 05	Jan. 06	Feb. 06	Mar. 06	Apr. 06	May 06	May 06 June 06 July 06		Aug. 06	Sept. 06	Oct. 06	Nov. 06	Dec. 06	Jan. 07	Feb. 07	Mar. 07
Focus Group Assembled	Completed	-															
Theoretical/Theological Section Complete							1 <sup>st</sup> Draft Submitted										
Focus Group meet			1st meet 2/0206	2 <sup>nd</sup> meet 2/23/06	3 <sup>rd</sup> meet 3/9/06					-	4th meet 09/27/06						
Initial web site Construction				Meeting	Meeting	Meeting	Meeting										
Invite to Participate in the Pre/Post Survey					Completed												
Survey Team selected					Completed												
Mailing of Pre-Survey						Completed											
Survey Collected						Completed											
Analysis of Pre-Survey										Completed							
Web site launched								Completed									
Enhancements to website											Completed Ongoing	Ongoing					
Post-Survey mailed									<u> </u>			Completed					
Post-Survey Analyzed													Completed				
Project reflection															Completed		

# APPENDIX E

NAMES AND TITLES OF THE MEMBERS OF THE FOCUS GROUP

#### Members of the Focus Group

Sr. Corita Ambro, CSJ, MSE
Program Director, Office of Disability Ministry
Catholic Charities Health & Human Services
Pastoral Associate, St. Augustine Church, Cleveland, OH
Director, St. Augustine Center

James E. Gepperth, M.P.A.
Program Director, Catholic Charities Family Center of Lorain, OH
Catholic Charities Health & Human Services

Mike Haggerty
Associate Exec Director, Catholic Charities Services Corp.
Catholic Charities Health & Human Services

Suzanne Joseph Director, Community and Residential Support Services Geauga County Board of MRDD

Mary Ann Masar Coordinator of Saint Gabriel Special Needs Programs

Rev. Joseph D. McNulty, MDiv, MTH Director, Office of Disability Ministry, Catholic Charities Health & Human Services Pastor, St. Augustine Church, Cleveland, OH

Maria A. Rivera

Management Analyst Defense Finance and Accounting Service (DFAS)-Cleveland Coordinator of the Disability Employment Special Emphasis Program DFAS-Cleveland

Dick Russ Managing Editor, WKYC-TV, Cleveland, Ohio

Sister Kathleen Ryan, SND Associate Director, The Commission on Catholic Community Action Catholic Charities Health & Human Services

Rev. Anthony J. Schuerger Pastor of St. Malachi, Parish and the Community of St. Malachi, Cleveland, OH

# APPENDIX F

BEATITUDES FOR PEOPLE WITH SPECIAL NEEDS

# BEATITUDES FOR PEOPLE WITH SPECIAL NEEDS

BLESSED ARE YOU who take time to listen to difficult speech, for you help us to know that if we persevere we can be understood.

BLESSED ARE YOU who walk with us in public places, and ignore the stares of strangers, for in your friendship we feel good to be ourselves.

BLESSED ARE YOU who never bid us to "hurry up" and, more blessed, you who do not snatch our tasks from our hands to do them for us, for often we need time rather than help.

BLESSED ARE YOU who stand beside us as we enter new and untried ventures, for our unsuredness will be outweighed by the times when we surprise ourselves and you.

BLESSED ARE YOU who ask for our help and realize our giftedness for our greatest need is to be needed.

BLESSED ARE YOU who help us with the graciousness of Christ, for often we need the help we cannot ask for.

BLESSED ARE YOU when, by all things, you assure us that what makes us individuals is not our particular disability or difficulty but our beautiful God-given personhood which no handicapping condition can confine.

REJOICE AND BE EXCEEDINGLY GLAD for your understanding and love have opened doors for us to enjoy life to its full and you have helped us believe in ourselves as valued and gifted people. 1777

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<sup>&</sup>lt;sup>177</sup> The Beatitudes for People with Special Needs, Date and publishing information unknown. A possible author may be Andre Masse. C.S.E. (NAMR Quarterly, 1968). The wording is different, but Masse's is the earliest version the author has found. The version presented here has been used by Catholic Charities Disability Services & Ministries for over 20 years.

# APPENDIX G

# FOCUS GROUP AGENDAS

G.1: FEBRUARY 2, 2006 G.2: MINUTES FOR THE FEBRUARY 2, 2006 MEETING G.3: SEPTEMBER 27, 2006

#### **G.1: February 2, 2006**

# Doctorate of Ministry Project Accessing Church through the Internet A New Approach to Evangelization to Persons with Disabilities

### Focus Group Meeting February 2, 2006 Agenda

#### Focus Group Members:

Sr. Corita Ambro, Rev. Tony Schuerger, Rev. Joseph McNulty, Maria Rivera, Sr. Kathleen Ryan, Sue Joseph, Mary Ann Masar, Jim Gepperth, Dick Russ, Mike Haggerty

- 1) Prayer
- 2) Introduction of Members
- 3) Overview of Doctorate Project
- 4) Project timeline
- 5) Evaluation of Survey Application
- 6) Evaluation of Pre-Survey
- 7) Questions
  - a) Is there a need for another meeting?
  - b) Should other people be part of this group or form a separate focus group?

#### **G.2**

# Doctorate of Ministry Project Accessing Church through the Internet A New Approach to Evangelization to Persons with Disabilities

#### Focus Group Meeting Minutes February 2, 2006

Attendance: Maria Rivera, Jim Gepperth, Mary Ann Masar, Fran Masar, Sue Joseph, Sr. Corita Ambro, Fr. Joe McNulty, Sr. Kathleen Ryan, Tracy Gretick, Mike Haggerty, Fr. Tony Schuerger, Dennis McNulty, Marilyn Scott

Excused: Dick Russ

- 1) Prayer
- 2) Introductions
- 3) Dennis explained his Doctorate program and why he asked everyone to be a part of this focus group
- 4) Timeline
  - a) explained focus group
  - b) explained survey group
  - c) explanation of website
- 5) Discussion followed. Below are comments/ideas from members of the focus group regarding the website:
  - Discussed which disabilities referring to for the website. Start broad. Look at the Church's teachings/Pastoral statements/Canon Law. Start general, then more specific, calling on others in the future to help build the website. Eventually have links for specific disabilities.
  - This is a great project now parents can access the info on their own possibly

     the same way they used to go to Dennis for info. Great that anyone can
     access the information in one place.
  - Idea is to give hope that the Church care many of these parents often feel very isolated.
  - Good idea would be to have those who visit the website be able to have input.
     Maybe consider a chatroom or blog, possibly in the future. This could break them out of their isolation by sharing ideas with each other.
  - Discussed a cross-cultural aspect. We in the US have information that we take for granted. With this medium, this website, we could share with other cultures immediately. There is nothing like this website across the US.
  - A common theme is that "the Church is accepting but also that persons with disabilities are included".

- One word Participation. This is a vehicle for anyone to participate.
- Primary Focus Access to Sacrament.
- This gives persons with disabilities a place to go for information, a sense of Hope. It encourages us to be able to help.
- People have a tendency to approach their Church when faced with a challenge.
- One thing that could develop is connection for community and religious leaders. Those who can't open their own sites can get persons in touch with others.
- Gives people an opportunity to share success stories. Families see someone is trying to help, this gives them Hope. The focus very often is on what is not, instead of on what is.
- Discussed Community. This brings them together gives them unity.
- Consider a Directory of Services/Programs, with contact info, where liturgies
  are signed, list of parishes who are already accessible, who will accept readers
  or Eucharistic ministers who ar blind, etc... Send out a survey to Churches on
  who has what explain the difference between accessible and inaccessible –
  is it inaccessible physically or attitudinally?
- Who are the "Dirty Dozen"???
- 6) Explanation of the two surveys
  - a) Survey Application this will be sent out to all priests, religious, religious educators, our newsletter. Of those who send back the application, 100 will be picked to be part of the Pre & Post Survey.
    - Suggestions include: Maybe choose a larger number than 100, to be sure you will get that many responses back.
    - Consider also sending to parents/families already in out programs.
  - b) Pre Survey
    - Identify the Target Population have people from that population look at the survey ahead of time. Is it clear for the rest? Is the terminology understandable?
    - Have clarity about what it is you want to find out.
    - The questions being asked are they what you intend them to mean? Many times people interpret things differently.
    - Talk to people who create surveys maybe have not be so open, focus it look at letter B on the survey.
- 7) Should Dennis add more focus groups / ask others about the website/surveys?
  - General consensus is No. "Too many opinions boggle the project!"
- 8) Should this Focus Group meet again?
  - Yes need to meet again to go over the Survey application and Pre survey.

**G.3** 

# Doctorate of Ministry Project Accessing Church through the Internet A New Approach to Evangelization to Persons with Disabilities

#### Focus Group Meeting #3 September 27, 2006 Agenda

Focus Group Members:

Sr. Corita Ambro, Rev. Tony Schuerger, Rev. Joseph McNulty, Maria Rivera, Sr. Kathleen Ryan, Sue Joseph, Mary Ann Masar, Jim Gepperth, Dick Russ, Mike Haggerty

- 1) Prayer
- 2) Evaluation of Post-Survey
- 3) Project timeline
- 4) Comments on the Website / Questions
- 5) Would the focus group want to function as on-going advisors to the website?

#### APPENDIX H

### PARTICIPANT COVER LETTERS AND SURVEYS

H.1: PARTICIPANT COVER LETTER AND PARTICIPANT QUESTIONNAIRE
H.2: COVER LETTER AND PRE-SURVEY
H.3: COVER LETTER AND POST-SURVEY

#### H.1: Participant Cover Letter and Participant Questionnaire

Dennis C. McNulty 7911 Detroit Avenue Cleveland, OH 44102 216-334-2962

March 1, 2006

Dear Friends,

I would like to ask your assistance in a project that will benefit the lives of persons with disabilities (cognitive disabilities (mr/dd), Deaf, hard of hearing, Blind and persons with mental illnesses) in our Diocese. I am asking you to consider being part of a 100 member survey group that would critique a website dedicated to presenting theological and practical information. The website would assist people with disabilities to be more integrated into our Church as fully participating members.

As the Director of Catholic Charities Disability Services for the last 19 years, I have met many parents of children with disabilities who encountered challenges as they tried to access the Sacraments for their child. This website is intended for them, but it is also intended to be valuable information on our Church's teachings for priests, religious, and persons with disabilities.

I would like to select 100 people who will commit to answering a pre-survey and a post-survey after visiting the website. Please take a moment to complete the enclosed brief participant questionnaire by **Wednesday**, **March 15**, **2006**, to help me select the 100 member survey group. In June, after the website is online, everyone can participate by visiting the website and evaluate it using the online survey.

This entire project is part of a Doctorate of Ministry program I began over one and a half years ago at St. Mary's Graduate School of Theology at the Center for Pastoral Leadership. The whole purpose of this Doctorate program was to create something useful for our Diocese in my area of ministry. This website is very possibly the first of its kind to present this type of information.

I want you to be assured that no Diocesan funds or Catholic Charities funds are being used to finance my studies or this Doctorate project. This project and the studies are being funded by personal resources.

Please consider this an opportunity to help create a new way for our Church to reach out and welcome people with different needs and different talents. Thank you for considering this offer. Please feel free to share this questionnaire with anyone you feel may be interested.

God Bless You,

Dennis C. McNulty

Please return the enclosed Survey Application no later than March 15, 2006, by using the enclosed self addressed envelope. You can save 39 cents by faxing it to me (please be sure to direct it to Dennis McNulty) at 216.334.2907 or if you have e-mail, contact me and I will send you an electronic copy. E-mail me at <a href="mailto:dmcnulty@clevelandcatholicchanties.org">dmcnulty@clevelandcatholicchanties.org</a>.

#### Participant Questionnaire

If you are interested in participating in the Survey Team, please complete the following information. This will assist me in the selection of 100 people to be part of the pre and post survey that will evaluate the website. Information supplied here will be used only for demographic purposes. You will remain anonymous. Your information, including your e-mail address, will not be shared without your specific permission.

Questio Be	ons: tween June, 2006 and (Check yes or no)	December 2006,	would you be wil	ling to:	
	Visit the website m     Yes	nonthly betw <b>ee</b> n Ju ∐No	ıne and Decembei	and provide feedba	ck
	• Evaluate the webs	ite by completing a ☐No	a pre and post surv	/ey	
	Receive follow up	qu <b>e</b> stions □No			
If you a need to	answered "No" to any o answer any more quo	of these questionestions.	ns, thank you for	your participation.	You do not
If you a	answered "Yes" to the	ab <b>ov</b> e, please co	mplete the follow	ving:	
A)	Contact Information:				
	Name				
	What is your e-mail add	dress?			
	Mailing Address				
-	Address		City	State	Zip
	What is your phone nu	mber?			
	What is your fax number	er?			
B) <sup>-</sup>	Tell me ab <mark>out yours</mark> elf				
1)	What is your age brack	ket? (Check one)			
	☐ 18 - 29 ☐ Over 80	30 - 49	<u>50 - 69</u>	☐ 70 – 79	
2)	What is your gender?	(Check one)			
[	☐ Male	Female			

3)	What is your race?	
	<ul><li>☐ White/Caucasian</li><li>☐ African American</li><li>☐ Hispanic/Latino</li><li>☐ Asian</li><li>☐ Pacific Islander</li><li>☐ Other</li></ul>	☐ American Indian/Alaskan Native☐ Biracial/Multiracial
4)	How would you best describe yourself? (Ch	neck as many as apply)
	☐ A parent of a person with a disability	A relative of a person with a disability
	☐ A priest	A Deacon
	A religious sister	A religious brother
	A Pastoral Minister	Other Religious tradition (please specify)
	☐ An advocate for persons with a disability	☐ A professional in the field of disabilities
	A volunteer in the field of disabilities	
	☐ I am a person with a disability. What type o	of disability? (Check as many as apply)  Hard of hearing
	☐ Blind / Visually disabled [	Cognitive disabilities (MR/DD)
	☐ Autism [	Mental Illness
	Physical challenges (i.e. use of a w	heelchair, cane, has c.p., m.s., etc.)
	☐ Multiple challenges	
	Other (please specify):	
	Other (please specify):	
5)	am familiar with the following types of disabili	ties:
	☐ Blind / Visually disabled	☐ Cognitive disabilities (MR/DD)
	☐ Autism	☐ Mental Illness
	Physical challenges (i.e. use of a w	heelchair, cane, has c.p., m.s., etc.)
	☐ Multiple challenges	
	Other (please specify):	
	☐ I have no experience or knowledge in the f	ield of disabilities.
6)	Other comments (use extra paper if needed):	

Thank you for completing this survey. Please return it to me no later than March 15, 2006 in the enclosed self-addressed envelope or fax it to 216.334.2907 (please mark clearly for Dennis McNulty) or email it to: <a href="mailto:dmcnulty@clevelandcatholiccharities.org">dmcnulty@clevelandcatholiccharities.org</a>

#### H.2: Cover Letter and Pre-Survey

Dennis C. McNulty 7911 Detroit Avenue Cleveland, OH 44102 216-334-2962

April 1, 2006

Dear Friends,

I am happy to inform you that you have been selected to be part of the survey team who have agreed to assist me in developing a website on theological issues that pertain to persons with disabilities in our Diocese. Without your participation, this project would not be possible. Thank you for your participation.

In March you completed the participant questionnaire and agreed that between June, 2006 and December, 2006 you would be willing to visit the website on a monthly basis, evaluate the website periodically and receive follow up questions. To assist you, I will send you reminders each month.

First thing I would like you to do would be to complete the enclosed pre-survey to help me build the website. As you complete this pre-survey, please keep in mind that our goal is to assist persons with disabilities to be more integrated into our Church as fully participating members. Any suggestions that you have will greatly assist me in creating this website. Please complete the pre-survey and return to me by Thursday, April 20, 2006.

Please note, this website is going to be built with your help. As such, the website will go online in a very rough form. It is my intention to create a website that we can continue to build as we go into the future. Once the website is online, I will send you information as to how to access it.

This is an opportunity to help create a new way for our Church to reach out and welcome people with different needs and different talents. Thank you for your participation.

God Bless You,

Dennis C. McNulty

Please return the enclosed/attached Pre-Survey no later than Thursday, April 20, 2006. You can e-mail it to me at <a href="mailto:dmcnulty@clevelandcatholiccharities.org">dmcnulty@clevelandcatholiccharities.org</a> or fax it to me at 216.334.2905.

#### Pre-Survey

This questionnaire has been designed to allow you to assist me in designing a website that will present theological and practical ways that assist persons with disabilities to participate more fully in our Church.

#### Aims of this project:

- 5. To determine the participants' level of understanding of Church teachings and pastoral practices in the area of ministry to persons with disabilities.
- 6. To determine the type of information that a theological and pastoral website should provide.
- 7. To provide information that would assist persons with disabilities, families, priests and pastoral ministers, etc. to further enhance an understanding of the Church's acceptance of persons with disabilities into the life of the Church.
- 8. To provide an interactive medium that could adapt to new questions and needs.

#### Let me define one term:

In this survey, the word, *Disability*, means any physical, intellectual, or emotional challenge that impacts a person's ability to function on a typical level. (cognitive disabilities (mr/dd), Deaf, hard of hearing, Blind and persons with mental illnesses)

ilinesses)		
Name (please print clearly):		
E-mail (please print clearly):		

#### Questions:

A) I would like to know about your knowledge of persons with disabilities and Church teachings concerning them.

Please check the response that applies to you:

1=	Strongly Disagree 2=Disagree 3=Neither Agree or Disagree	4= Agr	ee 5	= Stro	ngly A	gree
	Statement	1	2	3	4	5
1.	I think persons with disabilities feel accepted in the Church.					
2.	I feel familiar with Church teachings regarding persons with disabilities.					
3.	If asked advice on a specific question regarding the place of persons with disabilities in the Church I would feel confident to know where to find the Church's position.					
4.	I think that a website of theological and pastoral information would assist people in better understanding the Church's position.					
5.	I think that such a website would be of value to me.					

B) Now I would like to know what you think would be important to include on this website. In the space below write any suggestions that you can think of.
C) Below, I have listed a few possible topics that could be included in this website. Please check as many as you think would be important to include.
☐ The Catholic Church's teachings on persons with disabilities and their place
and/or role in the church.
☐ The rights of persons with disabilities regarding the Sacraments.
☐ Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.
Practical suggestions to assist persons with disabilities to participate more fully.
☐ Disability etiquette (How to act around persons with disabilities when you first meet them).
$\square$ How the Church's social justice principles apply to persons with disabilities.
$\square$ Current attitudes toward persons with disabilities and their historic causes.
$\square$ Current studies & surveys on the quality of life of persons with disabilities.
$\square$ Links to other websites that deal with disability issues and information.
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.
$\square$ Information concerning a specific disability.
D) Do you have any other comments on this project? (Use extra paper if needed)
Thank you for completing this survey. Please return it to me no later than Thursday, April 20, 2006. You can e-mail it to me at dmcnulty@clevelandcatholiccharities.org; or fax it to me at 216.334.2905.
Thank you for your assistance,
Dennis C. McNulty

#### H.3: Cover Letter and Post-Survey

Dennis C. McNulty 7911 Detroit Avenue Cleveland, OH 44102 216-334-2962

October 2, 2006

Dear Friends,

Enclosed, is your copy of the post-survey to evaluate the Catholic Disability Teachings Website (www.catholicdisabilityteachings.com).

Please return the survey by October 16, 2006. This will assist me in completing the project for my doctorate program.

If you wish to scan and email it, please return the survey to: <a href="mailto:dmcnulty@clevelandcatholiccharities.org">dmcnulty@clevelandcatholiccharities.org</a> or,

Fax to 216.334.2905

You can, of course, mail the survey to: Dennis C. McNulty

Dennis C. McNulty 7911 Detroit Avenue Cleveland, Ohio 44102

Thank you very much for participating in this project. It is our hope that this project will benefit the lives of people with disabilities. Your willingness to participate will assist persons with disabilities to be more integrated into our Church as fully participating members. It is your belief and your effort that will accomplish this.

May God Bless You!

Dennis C. McNulty

### Post - Survey

This post - survey will allow you to evaluate the Catholic Disability Teachings website.

The aims of the overall project are:

- 1. To determine the participants' level of understanding of Church teachings and pastoral practices in the area of ministry to persons with disabilities.
- 2. To determine the type of information that a theological and pastoral website should provide.
- 3. To provide information that would assist persons with disabilities, families, priests and pastoral ministers, etc. to further enhance an understanding of the Church's acceptance of persons with disabilities into the life of the Church.
- 4. To provide an interactive medium that could adapt to new questions and needs.

	needs.	, in the second second	
Name	(please print clearly):		
E-ma	il (please print clearly):		

#### Questions:

A) Respond to the following statements by checking the response that applies:

1=	Strongly Disagree 2=Disagree 3=Neither Agree or Disagree	4= Agı	ee S	S= Stro	ngly A	gree
	Statement	1	2	3	4	5
1.	This website was easy to use.					
2.	I found the material on this website easy to read and understand.					
3.	I was able to find the information I was interested in or searching for. $ \\$					
4.	My appreciation of Church's teachings and pastoral practices in the area of ministry to persons with disabilities has increased due to this website.					
5.	I feel that my suggestions and input helped shape the information contained on this website.					
6.	I think that the website assists people in better understanding the Church's teachings regarding persons with disabilities.					
7.	This website is of value to me.					
8.	I plan to visit this website as a source of information in the future.					

B) Which area(s) of the website was most helpful/informative to you?
C) Do you have any other comments on this project? (Use extra paper if needed)
D) Would you like to be notified periodically when the website is updated?  Yes \( \subseteq \text{ No } \subseteq \)
E) Would you like to receive the Catholic Charities Disability Services & Ministries E-Newsletter? Yes  No
Thank you for completing this survey. Please return it to me no later than Monday, October 16, 2006.
If you wish to email your survey to me, first save it to your desktop, then attach the completed survey in the email.
Send to dmcnulty@clevelandcatholiccharities.org
Or you can fax it to me at 216.334.2905. Or another option is to mail it to me at:
Dennis McNulty Disability Services 7911 Detroit Ave.

Thank you for your assistance. I sincerely appreciate your dedication and willingness to participate.

Cleveland, OH 44102

Dennis C. McNulty

#### APPENDIX I

# PARTICIPANT COMMENTS AND SUGGESTIONS

I.1: WEBSITE COMMENTS FOR JUNE 2006 I.2: WEBSITE COMMENTS FOR JULY 2006 I.3: WEBSITE COMMENTS FOR AUGUST 2006

#### I.1: Website Comments for June 2006

#### June Feedback

June 30, 2006

During the first month of the website 98 members of the survey team (31%) emailed me to make comments and suggestions. This is great considering that you did not have to respond at all!

31 responders (32%) wrote that they like the site.

67 responders (68%) made suggestions to improve the site.

I enjoyed all of your comments. Please don't hesitate to make suggestions. After all, that's what you volunteered for!

Some of the more common suggestions (in no particular order):

#### Aceessibility Issues:

A Person who has low vision suggested the following: Color is Dull. It must be larger and bolder. Link colors need to be darker Buttons (links) are difficult to read with that dark circle.

Individual who is blind suggested a "Go To Text" command to avoid a reading machine from reading all the links (This is one suggestion I am still trying to figure out.--- Dennis)

#### Font

Not legible for persons with visual challenges (Bold-Arial)
Font should be Consistent
Heading font is hard to read
Large Text Button

#### Wording

Should be understandable for school, staff and parent groups
Needs Pictures of People with Disabilities
(This is a hope for the future. For now I'm concentrating on information. --Dennis)

The page does not fit on my screen. (A technician told me it had to do with the "screen set up on your computer. Something about the amount of pixels. Again, I will see what I can do. --- Dennis)

#### Reminder for the visitor

To know where we are on each page

#### Suggestions of other information to add to the website

- Recreation Activities
- · Respite
- Refer to CBMRDD
- · CBMRD Calendar
- · What of other counties?
- · Community Resources
- Link to CCHHS—Newsletter?
- · Theological Information
- Search terms in website
- PSR classes
- · Accessible churches
- Copyright wording
- Activities Parish
- · Advocacy Program

#### I.2: Website Comments for July 2006

#### July Feedback

#### Website Comments for July

High points for the month:

- 439 individuals visited the site in July. This made a total of 1,001 visitors in two months!
- Visitor number 1,000 hit on the site on or around July 15th
- It was reported that around July 15th if you "googled" the words "Catholic Disability Teachings" that this site came up in the number one position out of over 1,000,000 sites.
- I tried "google-ing" the words "Catholic Teachings on Disabilities" and this site came up number 20 out of 3,330,000 sites.
- Several articles about this site appeared on websites and in our Cleveland Diocesan Newspaper.
- Several parishes requested permission to print articles on the website for their church bulletins.

Overall, it seemed a very good month... thanks to you!

Total comments for the month were 72 Specific suggestions came from 46 (64%) participants.

Information that has been requested for the website:

- List of PSR/Classes
- List of Parish Advocates
- Hospice Care
- Signed Liturgies
- Accessible Churches
- Diocesan Contact Persons

These suggestions bring up many thoughts as to where these pieces of information needs to be placed. They could be placed here but we are considering placing specific opportunities on the Diocesan website of <u>Catholic Charities Disability Services</u> and ministries

Thanks to your suggestions, we are about to begin a survey of parishes in our diocese to answer the information you are requesting.

Some of the other, more common comments or suggestions (in no particular order):

- Overall, people felt that the website was easier to read with the new font and background.
- · Change the title of an organization from AAMR to AAIDD
- Cut first paragraph of "Who We Are"
- Icons for Resource Page would help.

- Title Each Page so the visitor knows where they are
- Resources
  - o The Alphabetical listing is good
  - Perhaps by categories (national, local, Ohio, county, by type of disability) (Dennis' comment: This last one may be tough. Many websites cover numerous types of disabilities)
- Bulletin board for people to share
- Pictures/Graphics/Graphs
- You Will not Please Everyone
- Definitions—need a disclaimer
  - o Insulting to lump individuals with disabilities into a category
  - o Too Clinical
- County Boards—A listing of individual County Boards
- · Buttons could be bolder
- Need to have the site "Bobby Approved."

#### I.3: Website Comments for August 2006

#### August Feedback

#### Website Comments for August

An important note...Several of you noticed that I had changed the email address to contact me to <a href="mailto:cdt0601@cheerful.com">cdt0601@cheerful.com</a> This is an address that was set up to receive your emails. I was advised that it is dangerous to use my day to day email address on a website. Doing this helps to eliminate spam mail. Please know that the email is actually coming to me directly.

High points for the month:

- 554 individuals visited the site in August. This made a total of 1,555 visitors in three months!
- Parishes continue to request permission to print articles on the website for their church bulletins.
- The geographic area that the website is impacting seems to be widening. During August comments, questions and emails arrived from New Jersey, Maryland and North Dakota, to name a few. Thank you to all who are sharing this website!

Total comments for the month were 63

Some of the other, more common comments or suggestions (in no particular order):

- Most people liked the new additions.
- The quote "big hit" of the month: 1) The Etiquette page; 2) The Definition page. The difference is people like the Etiquette page but haven't stopped fighting about the Definition page. It is really great to hear you voice your opinions.
- The website seems to be too oriented toward children. The website needs young adult and adult resources. The website is focused too much on children than adults.
  - (I agree that so far the resources that have been posted on this website have been mostly directed towards parents or children with disabilities, but up till now, that has been the major request. If you have resources or specific requests, let me know.)
- In the Church Teachings section, shorten the intro.
- Site the source for IDEA (Individual with Disabilities Education Act see Resource page).
- · List parishes with advocates
- This site should be promoted in the Universe Bulletin, parish bulletin and district meetings. (the UB did publish an article - see bottom part of July's comments - click <u>here</u>)
- There needs to be tips on how to include everyone in the church liturgy.
- A suggestion to include a "Did you Know?" page that would highlight parish initiatives. (This would be very easy to accomplish - feel free to send in what your parish is doing for persons with disabilities and I will begin to construct such a page.)

#### APPENDIX J

ARTICLE FROM THE CATHOLIC UNIVERSE BULLETIN ON CATHOLICDISABILITYTEACHINGS.COM PUBLISHED JUNE 30, 2006 Web Site Shares Church's Teachings on People With Disabilities
By Dennis Sadowski, Editor
Catholic Universe Bulletin, Vol. 132, No. 26,
Cleveland Catholic Diocese, June 30, 2006

A new Web site being developed by an arm of the diocesan Catholic Charities system is helping spread church teachings on the life of people with disabilities within the church.

Dennis McNulty, director of Catholic Charities Disability Services for the diocese, is developing the site to provide accurate information about the church's teachings on how people with disabilities can have fuller access to the sacraments.

"The Web site is meant to be another tool to communicate with people," McNulty explained. The site can be accessed at <a href="https://www.catholicdisabilityteachings.com">www.catholicdisabilityteachings.com</a>.

The idea for the site has been percolating in McNulty's mind for several years, but it wasn't until he enrolled in the doctor of ministry program at St. Mary Seminary and Graduate School of Theology in 2004 that he decided to incorporate its development as part of his studies.

McNulty said he has talked with people with disabilities and parents of children

Michalty said he has talked with people with disabilities and parents of children with disabilities who were "upset and confused" because of obstacles to full participation in church life, namely receiving the sacraments.

"There was no place for parents to get information on what the church believes," McNulty said.

With site up and running, McNulty said he's hopeful that others will begin to understand that "the church does welcome people with disabilities."

Still under construction, the Web site currently provides information or links to statements from the Vatican and U.S. bishops and inspirational prayers and reflections. As the site is developed, McNulty plans to add a list of resources, practical suggestions to assist people with disabilities to experience church life more fully, social justice as it pertains to people with disabilities and an online survey to allow respondents to comment on the site and offer ideas for new pages of information.

During the first weeks of operation, McNulty has received numerous comments about what other information to include. He also has been approached by people around the country asking to link to it.

"More than their responses there has been a few people who have e-mailed me that they have no idea that the church had such strong feelings for people with disabilities." he said.

#### APPENDIX K

RESPONSES BY SUBGROUPS TO THE FIVE STATEMENTS OF THE PRE-SURVEY

#### Responses by Subgroups to the Five Statements of the Pre-Survey Results

The team members were first asked to respond to five statements. These statements were to determine the participants' knowledge of church teachings concerning persons with disabilities and their feeling as to the value of a website presenting these teachings. Responses were based on a likert scale of 1 to 5 (I=Strongly Disagree, 2=Disagree, 3 =Neither Agree or Disagree, 4= Agree, 5= Strongly Agree) and were made in response to the following statements:

- 1. I think persons with disabilities feel accepted in the church.
- 2. I feel familiar with church teachings regarding persons with disabilities
- 3. If asked advice on a specific question regarding the place of persons with disabilities in the church I would feel confident to know where to find the church's position.
- 4. I think that a website of theological and pastoral information would assist people in better understanding the church's position.
  - 5. I think that such a website would be of value to me.

	Que	stion#								
Response	1		2		3	4			5	
	#	%	#	%	#	%	#	%	#	1 %
Strongly Agree	3	3%	14	14%	17	18%	63	64%	52	549
Agree	18	19%	39	40%	26	27%	26	26%	31	329
Neither Agree or Disagree	46	47%	16	16%	15	16%	4	4%	10	109
Disagree	27	28%	22	23%	29	30%	3	3%	1	1%
Strongly Disagree	3	3%	6	6%	g	9%	3	3%	3	3%
Total	97	100%	97	100%	96		99		97	
Deacon										
	Outos	tion#								
Response	1	1101111	2		3 4				5	
Strongly Disagree	#	1 %	#	%	#	%	#	%	#	1 %
Strongly Agree	1	20%	0	0%	0	0%	2	40%	2	40%
Agree	0	0%	3	75%	2	40%	2	40%	3	60%
Neither Agree or Disagree	3	60%	1	25%	2	40%	1	20%	0	0%
Disagree	1	20%	0	0%	0	0%	0	0%	0	0%
Strongly Disagree	0	0%	0	0%	1	20%	0	0%	0	0%
Grand Total	5		4		5		5		5	
			··							
			_							-

Response	1		2	2		3		4		
Strongly Disagree	#	%	#	%	#	%	#	%	5 #	1 %
Strongly Agree	1	17%	0	0%	0	0%	2	40%	2	409
Agree	1	17%	3	75%	2	40%	2	40%	3	609
Neither Agree or Disagree	2	33%	1	25%	2	40%	1	20%	0	0%
Disagree	1	17%	0	0%	0	0%	0	0%	0	0%
Strongly Disagree	1	17%	0	0%	1	20%	0	0%	0	0%
Grand Total	6		4		5		5		5	
Parent of Person with a Disability										
1,,	Question#					I			1	1
Response	1		2		3		4	<u> </u>	5	1
,	#	%	#	%	#	%	#	%	#	%
Strongly Agree	6	10%	6	10%	4	7%	38	58%	34	55°
Agree	12	20%	15	24%	13	21%	19	29%	19	319
Neither Agree or Disagree	24	39%	15	24%	11	18%	2	3%	5	8%
Disagree	17	28%	20	32%	23	38%	3	5%	1	2%
Strongly Disagree	2	3%	6	10%	10	16%	3	5%	3	5%
Grand Total	61	270	62	1070	61	1070	65	070	62	37
Pastoral Minister										
	Question#									
Response	1		2		3		4		5	
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	0	0%	3	19%	3	19%	11	69%	12	759
Agree	2	13%	8	50%	- 8	50%	5	31%	3	19%
Neither Agree or Disagree	7	44%	3	19%	2	13%	0	0%	1	6%
Strongly Disagree	0	0%	1	6%	1	6%	0	0%	0	0%
Disagree	7	44%	1	6%	2	13%	0	0%	0	0%
Grand Total	16		16		16		16		16	
Person With a Disability										
	Question#									1
Response	1		2		3		4		5	-
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	2	7%	5	18%	2	7%	17	61%	15	54%
Agree	4	14%	10	36%	8	29%	7	25%	g	32%
Veither Agree or Disagree	9	32%	5	18%	10	36%	4	14%	4	14%
Disagree	11	39%	5	18%	7	25%	0	0%	0	0%
Strongly Disagree	2	7%	3	11%	1	4%	0	0%	0	0%
Grand Total	28	93%	28	82%	28	0.9286	28	0.3929	28	

				<u> </u>		1		1		
	Question#									
Response	1		2		3		4		5	
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	1	4%	4	17%	2	8%	12	50%	12	50%
Agree	6	25%	g	38%	13	54%	8	33%	8	339
Neither Agree or Disagree	7	29%	8	33%	5	21%	2	8%	2	8%
Disagree	10	42%	3	13%	3	13%	2	8%	2	8%
Strongly Disagree	0	0%	0	0%	1	4%	0	0%	0	0%
Grand Total	24	42%	24	13%	24	0.1667	24	0.0833	24	
Professional in Field of Disabilities										
	Question#							'		1
Response	1		2		3		4		5	
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	4	4%	13	13%	13	13%	53	55%	40	41%
Agree	30	32%	35	36%	20	21%	35	36%	36	379
Neither Agree or Disagree	43	45%	20	21%	20	21%	5	5%	18	189
Disagree	16	17%	22	23%	38	39%	1	1%	1	1%
Strongly Disagree	2	2%	7	7%	6	6%	3	3%	3	3%
Grand Total	95		97		97		97		98	
	Question#									
Response	1		2		3		4		5	
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	5	8%	8	12%	10	15%	34	52%	30	45%
Agree	16	25%	22	33%	17	26%	25	38%	25	38%
Neither Agree or Disagree	32	49%	11	17%	12	18%	2	3%	8	12%
Disagree	11	17%	20	30%	19	29%	2	3%	1	2%
Strongly Disagree	1	2%	5	8%	8	12%	2	3%	2	3%
Grand Total	65		66		66		65		66	
D.P. L. D. W.										
Religious Brother	A !!									
_	Question#				_					
Response	1		2		3		4		5	
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	0	0%	0	0%	0	0%	1	50%	1	50%
	0	0%	1	50%	1	50%	1	50%	1	50%
Agree	0	0%	1	50%	1	50%	0	0%	0	0%
Neither Agree or Disagree				001		00/	0	004		00/
Neither Agree or Disagree Disagree	2	100%	0	0%	0	0%	U	0%	0	0%
Neither Agree or Disagree		100% 0%	0	0%	0	0%	0	0%	0	0%

	Question#									
Response	1		2 3			4	5			
,	#	%	#	%	#	%	#	1 %	#	%
Strongly Agree	3	20%	2	13%	4	25%	4	25%	2	13%
Agree	4	27%	4	25%	4	25%	0	0%	0	0%
Neither Agree or Disagree	0	0%	4	25%	4	25%	11	69%	11	69%
Disagree	8	53%	3	19%	1	6%	0	0%	2	13%
Strongly Disagree	0	0%	3	19%	3	19%	1	6%	1	6%
Grand Total	15	100%	16	100%	16	1	16	1	16	1
Volunteer										
	Question#							·		
Response	1		2		3		4		5	
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	5	10%	7	13%	7	13%	37	69%	37	69%
Agree	12	23%	22	41%	18	34%	10	19%	7	13%
Neither Agree or Disagree	21	40%	12	22%	8	15%	2	4%	8	15%
Disagree	12	23%	10	19%	18	34%	3	6%	0	0%
Strongly Disagree	2	4%	3	6%	2	4%	2	4%	2	4%
Grand Total	52	100%	54	100%	53	1	54	1	54	1
Other										
	Question#									
Response	1		2		3		4		5	
	#	%	#	%	#	%	#	%	#	%
Strongly Agree	1	5%	3	14%	1	5%	8	38%	6	29%
Agree	6	29%	1	5%	4	19%	10	48%	10	48%
Neither Agree or Disagree	10	48%	g	43%	5	24%	2	10%	3	14%
Disagree	4	19%	4	19%	6	29%		0%	1	5%
Strongly Disagree	0	0%	4	19%	5	24%	1	5%	1	5%
Grand Total	21	100%	21	100%	21	1	21	1	21	1

#### APPENDIX L

RESPONSES BY SUBGROUPS TO PART C OF THE PRE-SURVEY

# Responses by Subgroups to Part C of the Pre-Survey

## SUGGESTED TOPICS BY RESPONDENT DESCRIPTION

Advocate for persons with a disability	Total:	123
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	12	10%
Current attitudes toward persons with disabilities and their historic causes.	6	5%
Current studies & surveys on the quality of life of persons with disabilities.	6	5%
Disability etiquette (How to act around persons with disabilities when you first meet them).	11	9%
How the Church's social justice principles apply to persons with disabilities	10	8%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	17	14%
Information concerning a specific disability. (offer "tidbits" each time you update website)	19	15%
Links to other websites that deal with disability issues and information.	12	10%
Practical suggestions to assist persons with disabilities to participate more fully.	14	11%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	13	11%
The rights of persons with disabilities regarding the Sacraments.	11	9%

Deacon	Total:	5
Disability etiquette (How to act around persons with disabilities when you first meet them).	1	20%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	1	20%
Practical suggestions to assist persons with disabilities to participate more fully.	2	40%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	1	20%
and/or role in the original.		2070

Other	Total:	22
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	2	9%
Current attitudes toward persons with disabilities and their historic causes.	2	9%
Current studies & surveys on the quality of life of persons with disabilities.	2	9%
Disability etiquette (How to act around persons with disabilities when you first meet them).	3	14%
How the Church's social justice principles apply to persons with disabilities	1	5%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	2	9%
Information concerning a specific disability.	2	9%
Links to other websites that deal with disability issues and information.	2	9%
Practical suggestions to assist persons with disabilities to participate more fully.	2	9%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	3	14%
The rights of persons with disabilities regarding the Sacraments.	1	5%

Other Religious Tradition	Total	8
Current attitudes toward persons with disabilities and their historic causes.	2	25%
Disability etiquette (How to act around persons with disabilities when you first meet them).	1	13%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	1	13%
Information concerning a specific disability.	1	13%
Practical suggestions to assist persons with disabilities to participate more fully.	2	25%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	1	13%

Parent of person with a disability	Total	92
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	10	11%
Current attitudes toward persons with disabilities and their historic causes.	2	2%
Current studies & surveys on the quality of life of persons with disabilities.	7	8%
Disability etiquette (How to act around persons with disabilities when you first meet them).	6	7%
How the Church's social justice principles apply to persons with disabilities	8	9%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	6	7%
Information concerning a specific disability.	6	7%
Links to other websites that deal with disability issues and information.	9	10%
Practical suggestions to assist persons with disabilities to participate more fully.	9	10%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	12	13%
The rights of persons with disabilities regarding the Sacraments.	16	17%

Pastoral Minister	Total	19
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	2	11%
Current studies & surveys on the quality of life of persons with disabilities.	2	11%
How the Church's social justice principles apply to persons with disabilities	2	11%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	1	5%
Links to other websites that deal with disability issues and information.	6	32%
Practical suggestions to assist persons with disabilities to participate more fully.	4	21%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	11_	5%
The rights of persons with disabilities regarding the Sacraments.	1	5%

Person with a disability	Total	44
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	4	9%
Current attitudes toward persons with disabilities and their historic causes.	2	5%
Current studies & surveys on the quality of life of persons with disabilities.	5	11%
Disability etiquette (How to act around persons with disabilities when you first meet them).	4	9%
How the Church's social justice principles apply to persons with disabilities	3	7%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	7	16%
Information concerning a specific disability.	3	7%
Links to other websites that deal with disability issues and information.	4	9%
Practical suggestions to assist persons with disabilities to participate more fully.	3	7%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	4	9%
The rights of persons with disabilities regarding the Sacraments.	5	11%

Priest	Total	27
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	2	7%
Current studies & surveys on the quality of life of persons with disabilities.	2	7%
Disability etiquette (How to act around persons with disabilities when you first meet them).	2	7%
How the Church's social justice principles apply to persons with disabilities	1	4%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	2	7%
Information concerning a specific disability.	4	15%
Links to other websites that deal with disability issues and information.	6	22%
Practical suggestions to assist persons with disabilities to participate more fully.	4	15%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	3	11%
The rights of persons with disabilities regarding the Sacraments.	1	4%

Professional in field of disabilities	Total	120
***Links to other websites that deal with disability issues and information.	1	1%
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	11	9%
Current attitudes toward persons with disabilities and their historic causes.	8	7%
Current studies & surveys on the quality of life of persons with disabilities.	7	6%
Disability etiquette (How to act around persons with disabilities when you first meet them).	15	13%
How the Church's social justice principles apply to persons with disabilities	9	8%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	9	8%
Information concerning a specific disability.	7	6%
Links to other websites that deal with disability issues and information.	12	10%
Practical suggestions to assist persons with disabilities to participate more fully.	12	10%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	15	13%
The rights of persons with disabilities regarding the Sacraments.	14	12%

Relative of a person with a disability	Total	89
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	9	10%
Current attitudes toward persons with disabilities and their historic causes.	5	6%
Current studies & surveys on the quality of life of persons with disabilities.	5	6%
Disability etiquette (How to act around persons with disabilities when you first meet them).	7	8%
How the Church's social justice principles apply to persons with disabilities	12	13%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	14	16%
Information concerning a specific disability.	3	3%
Links to other websites that deal with disability issues and information.	7	8%
Practical suggestions to assist persons with disabilities to participate more fully.	8	9%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	9	10%
The rights of persons with disabilities regarding the Sacraments.	10	11%

Religious brother	Total	3
Links to other websites that deal with disability issues and information.	1	33%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	1	33%
The rights of persons with disabilities regarding the Sacraments.	1	33%

Religious sister	Total	19
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	11_	5%
Current attitudes toward persons with disabilities and their historic causes.	2	11%
Current studies & surveys on the quality of life of persons with disabilities.	3	16%
How the Church's social justice principles apply to persons with disabilities	2	11%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	2	11%
Links to other websites that deal with disability issues and information.	1	5%
Practical suggestions to assist persons with disabilities to participate more fully.	3	16%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	1	5%
The rights of persons with disabilities regarding the Sacraments.	4	21%

Volunteer	Total	65
Canon Law (the laws of the Church) and what they say about persons with disabilities participating in the Sacraments.	6	9%
Current attitudes toward persons with disabilities and their historic causes.	6	9%
Current studies & surveys on the quality of life of persons with disabilities.	1_	2%
Disability etiquette (How to act around persons with disabilities when you first meet them).	7	11%
How the Church's social justice principles apply to persons with disabilities	7	11%
How to develop an accessible church: one that is physically, sacramentally and attitudinally accessible.	3	5%
Information concerning a specific disability.	5	8%
Links to other websites that deal with disability issues and information.	6	9%
Practical suggestions to assist persons with disabilities to participate more fully.	10	15%
The Catholic Church's teachings on persons with disabilities and their place and/or role in the Church.	9	14%
The rights of persons with disabilities regarding the Sacraments.	5	8%

## APPENDIX M

COMPARISON OF THE DEMOGRAPHICS OF THE PARTICIPANT QUESTIONNAIRE WITH THE DEMOGRAPHICS OF THE POST-SURVEY

M.1: COMPARISON OF RESPONDENTS BY SUBGROUP M.2: COMPARISON OF OVERALL DEMOGRAPHICS M.3: GRAPHS COMPARING OVERALL DEMOGRAPHICS

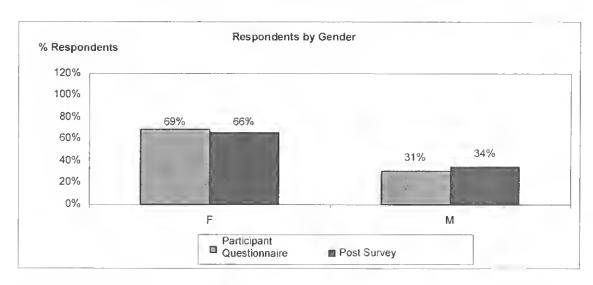
M.1: Comparison of Respondents by Subgroup

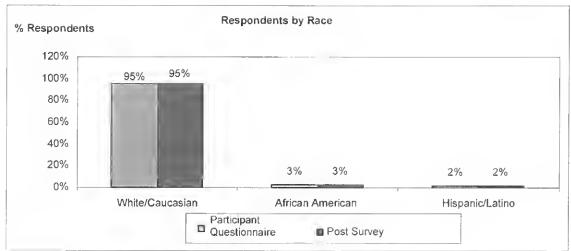
Describe Self	# Responding to Participant Questionnaire	# Responding to Post- Survey	# Remaining
All Categories Advocate for persons with a	317	190	127
disability Deacon	99 5	74 5	25 0
Other Religious Tradition	6	6	0
Parent of person with a disability	65	44	21
Pastoral Minister	16	15	1
Person with a disability	28	20	8
Priest	24	14	10
Professional in field of disabilities	98	81	17
Relative of a person with a disability	66	55	11
Religious brother	2	3	-1
Religious sister	16	13	3
Volunteer	54	40	14
Other	21	13	8

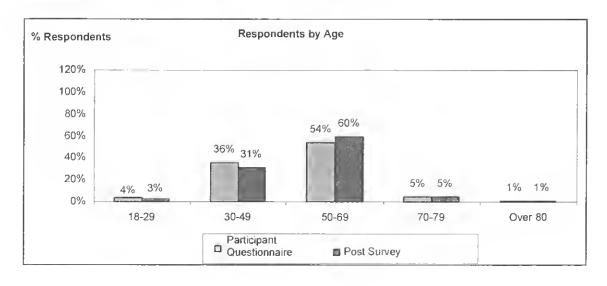
## M.2: Comparison of Overall Demographics

Participant Que	estionnaire		Post Survey	7	
Gender	Count	Percentage	Gender	Count	Percentage
F	161	66%		0	
M	83	34%	F	125	66%
	244		M	63	34%
				188	
Race	Count	Percentage	Race	Count	Percentage
African			African		
American	7	3%	American	7	4%
Asian & Pacific Islander	1	0%	Hispanic/Latino	3	2%
Hispanic/Latino	5	2%	White/Caucasian	177	95%
White/Caucasian	229	95%		187	
	242				
Age	Count	Percentage	Age	Count	Percentage
	0			0	
18-29	11	4.5%	18-29	5	2.7%
30-49	87	35.8%	30-49	59	31.6%
50-69	131	53.9%	50-69	112	59.9%
70-79	11	4.5%	70-79	9	4.8%
Over 80	3	1.2%	Over 80	2	1.1%

## M.3: Graphs Comparing Overall Demographics







## APPENDIX N

# RESPONSES BY SUBGROUPS TO THE EIGHT STATEMENTS OF THE POST SURVEY

### Responses by Subgroups to the Eight Statements of the Post Survey

## Questions:

- 1. This website was easy to use.
- 2. I found the material on this website easy to read and understand.
- 3. I was able to find the information I was interested in or searching for.
- 4. My appreciation of the Church's teachings and pastoral practices in the area of ministry to person with disability has increased due to this website.
- 5. I feel that my suggestions and input helped shape the information contained on this website.
- 6. I think that the website assists people in better understanding the church's teachings regarding persons with disabilities.
- 7. This website is of value to me.

													ļ			
Advocate for Persons v	with disabi	ilities														
	Que	stions					-									
Response	1		2		3		4		5		6		7		8	
Strongly Agree	42	58%	46	62%	34	46%	33	45%	26	35%	47	64%	42	57%	43	59%
Agree	28	38%	26	35%	29	39%	28	38%	26	35%	24	32%	27	36%	24	33%
Neither Agree nor Disagree	3	4%	2	3%	9	12%	12	16%	19	26%	3	4%	4	5%	5	7%
Disagree	0	0%	0	0%	1	1%	1	1%	3	4%	0	0%	1	1%	1	1%
Strongly Disagree	0	0%	0	0%	1	1%	0	0%	0	0%	0	0%	0	0%	0	0%
TOTAL	73		74		74		74		74		74		74		73	
Deacon														1		
	Que	stions						1		1				!		
Response	ı		2		3		4		5		6		7		8	
Strongly Agree	2	40%	2	40%	2	40%	2	40%	2	40%	2	40%	2	40%	2	40%
Agree	3	60%	3	60%	3	60%	3	60%	2	40%	3	60%	2	40%	3	60%
Neither Agree nor Disagree	0	0%	0	0%	0	0%	0	0%	1	20%	0	0%	1	20%	0	0%
Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
TOTAL	5		5		5		5		5		5		5		5	
Other Religious Tradit	iou															
		slions														
Response	i		2		3		4		5		6		7		8	
Strongly Agree	2	40%	4	67%	2	33%	4	67%	0	0%	5	83%	2	33%	4	67%
Agree	3	60%	2	33%	3	50%	1	17%	3	50%	1	17%	4	67%	2	33%
Neither Agree nor Disagree	0	0%	0	0%	1	17%	1	17%	2	33%	0	0%	0	0%	0	0%
Disagree	0	0%	0	0%	0	0%	0	0%	- 1	17%	0	0%	0	0%	0	0%
Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
TOTAL	5		6		6		6		6		6		6		6	

	One	stions			,		1	1	1		1	1				
Dasmanas	1	.5410113	2		2				-						0	
Response	24	55%		I c co/	3	Lagar	4	1 410/	5	L 220/	6	1 4007	7	T 420/	8	1 404
Strongly Agree			24	55%	12	27%	18	41%	10	23%	21	48%	19	43%	21	48
Agree	17	39%	16	36%	23	52%	21	48%	19	43%	18	41%	23	52%	18	41
Neither Agree nor Disagree	2	5%	3	7%	6	14%	5	11%	11	25%	4	9%	2	5%	3	75
Disagree	1	2%	0	0%	2	5%	0	0%	1	2%	1	2%	0	0%	2	55
Strongly Disagree	0	0%	1	2%	1	2%	0	0%	1	2%	0	0%	0	0%	0	0'
TOTAL	44		44		44		44		42		44		44		44	
Pastoral Minister				-												-
	Que	stions			<u></u>	<u> </u>		l				1	l	1		1
Response	1		2		3		4		5		6		7		8	
Strongly Agree	6	40%	7	47%	7	47%	7	47%	5	33%	12	80%	9	60%	9	60
Agree	8	53%	7	47%	7	47%	5	33%	4	27%	2	13%	5	33%	5	33
Neither Agree nor Disagree	1	7%	0	0%	0	0%	2	13%	6	40%	1	7%	0	0%	0	09
Disagree	0	0%	I	7%	1	7%	1	7%	0	0%	0	0%	1	7%	ı	79
Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	09
TOTAL	15		15		15		15		15		15		15		15	
is 1. 1. 1.41.																
Person with a disability		stions														
Response	1	1	2		3		4	_	5		6		7		8	
Strongly Agree	13	65%	10	53%	9	47%	7	35%	5	25%	10	50%	9	45%	9	45
Agree	5	25%	7	37%	5	26%	11	55%	8	40%	9	45%	9	45%	9	45
Neither Agree nor Disagree	2	10%	1	5%	3	16%	1	5%	6	30%	1	5%	1	5%	1	5%
Disagree	0	0%	1	5%	]	5%	I	5%	I	5%	0	0%	1	5%	1	59
Strongly Disagree	0	0%	0	0%	ı	5%	0	0%	0	0%	0	0%	0	0%	0	09
TOTAL	20		19		19		20		20		20		20		20	
Priest																
	Ques	stion#														
Donnonno		, crount	2		2		- 1		-	_			7		0	
Response	10	71%	10	71%	3	57%	6	43%	5	33%	6	64%	7	50%	8	20
Strongly Agree	4	29%	3	21%		<u> </u>				L			7		5	36
			3 I	7%	0	43% 0%	3	36% 21%	4	33%	5	36%	6	43% 7%	3	43 <sup>1</sup>
Strongly Agree Agree Neither Agree nor	0	0%														
Agree Neither Agree nor Disagree	0			007	0	007	0	007	0	007	^	007	0	00/	^	0.0
Agree Neither Agree nor Disagree Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	09
Agree Neither Agree nor Disagree	0			0%	0 0 14	0%	0 0	0% 0%	0 0 12	0% 0%	0 0 14	0%	0 0 14	0%	0	09 09

	Que	stion#		•	,					1		1		1		1
Response	1		2		3		4		5		6		7		8	
Strongly Agree	46	57%	48	59%	32	39%	27	33%	22	27%	47	57%	39	T 48%	37	46%
Agree	32	40%	31	38%	41	50%	36	44%	36	44%	30	37%	34	41%	34	42%
Neither Agree nor Disagree	3	4%	3	4%	9	11%	17	21%	21	26%	5	6%	6	7%	9	11%
Disagree	0	0%	0	0%	0	0%	2	2%	3	4%	0	0%	2	2%	0	0%
Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	1	1%	1	1%
TOTAL	81		82		82		82		82		82		82		81	
Relative of a person w	ith a disab	ility														
-	Que	stions			J		<u> </u>	-		1		1	Į			1
Response	1		2		3		4		5		6		7		8	
Strongly Agree	31	57%	29	54%	23	43%	18	33%	13	24%	31	56%	26	47%	27	50%
Agree	20	37%	23	43%	26	48%	27	49%	25	46%	20	36%	24	44%	22	41%
Neither Agree nor Disagree	3	6%	2	4%	3	6%	9	16%	15	28%	4	7%	4	7%	5	9%
Disagree	0	0%	0	0%	1	2%	1	2%	1	2%	0	0%	1	2%	0	0%
Strongly Disagree	. 0	0%	0	0%	1	2%	0	0%	0	0%	0	0%	0	0%	0	0%
TOTAL	54		54		54		55		54		55		55		54	
Religious brother	Que	stions														
Response	1	311011.5	2		3		4		5		6		7		8	
Strongly Agree	2	67%	2	67%	2	67%	1	33%	0	0%	1	33%	1	33%	1	33%
Agree	1	33%	1	33%	1	33%	2	67%	1	50%	2	67%	1	33%	1	33%
Neither Agree nor Disagree	0	0%	0	0%	0	0%	0	0%	1	50%	0	0%	1	33%	1	33%
Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
TOTAL	3		. 3		3		3		2		3		3		3	
Religious sister												_				
	Ques	stion#														
Response	ŀ		2		3		4		5		6		7		8	
Strongly Agree	5	38%	6	46%	4	31%	5	38%	5	38%	11	85%	6	46%	7	54%
Agree	7	54%	6	46%	6	46%	5	38%	3	23%	l	8%	4	31%	5	38%
Neither Agree nor	1	8%	0	0%	2	15%	2	15%	5	38%	1	8%	2	15%	0	0%
Disagree	0	0%	1	8%	1	8%	ŀ	8%	0	0%	0	0%	1	8%	1	8%
Disagree				1												
	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%

Volunteer																
	Que	stion#						-	-							
Response	1	1		2			4		5		6		7		8	
Strongly Agree	25	63%	25	64%	17	44%	15	38%	9	23%	25	63%	22	55%	26	65%
Agree	14	35%	14	36%	17	44%	21	53%	18	45%	13	33%	16	40%	12	30%
Neither Agree nor Disagree	1	3%	0	0%	4	10%	3	8%	11	28%	2	5%	1	3%	2	5%
Disagree	0	0%	0	0%	1	3%	1	3%	2	5%	0	0%	1	3%	0	0%
Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
TOTAL	40		39		39		40		40		40		40		40	
Other																
	Que	stion#														
Response	1		2		3		4		5		6		7		8	
Strongly Agree	7	54%	8	62%	4	31%	7	54%	2	15%	8	62%	6	46%	7	54%
Agree	6	46%	5	38%	7	54%	4	31%	1	8%	5	38%	6	46%	4	31%
Neither Agree nor Disagree	0	0%	0	0%	2	15%	2	15%	10	77%	0	0%	1	8%	2	15%
Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Strongly Disagree	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
TOTAL	13		13		13		13		13		13		13		13	

## APPENDIX O

SUBGROUP'S CHOICES OF FAVORITE WEBSITE PAGES

## **Subgroup's Choices of Favorite Website Pages**

	Total	22	က	2	1	12	96		4	7	7	72		12	10	4		63	111	4		9	24	
ř	Other	2				2	(2)		-	-		ന		-	2	-		က	က				-	
	Religious Brother	-					2							-				-	-				Į.	
lebsite	Religious Sister	-					2					2							3				2	
Subgroups' Choices of the Most Helpful or Informative Area(s) of the Website	Other Religious Tradition											2						1	4				•	
ive Are	Deacon						4																	
r Informat	Pastoral Minister	-					9					ဗ		-					7					
ielpful o	Relative	4	-	-		-	10		5	1	-	13		2	က	-		9	14			-	7	
he Most H	Professional	ო		-	-	2	13		-	-	_	16		2	2			4	56	-		2	4	
es of t	Priest	E	-				4				-	က		2	-			7	2					
ps' Choic	Person w/ disabilities	-					7					4		-				4	4				-	
ubgrou	Volunteer	8				2	13		က	2	2	7		-	_			တ	12	-		-	<b>*</b>	
တ	Advocate	2	-	2		3	23		ന	-		=		•	-	-		Ξ	22	2		5	9	
	Parent			-		2	6		+	-	1	æ				-		æ	10			,	-	
		Home Page	Search	News	Feedback	Who We Are	Church	Teachings	Canon Law	US Bishops	Sacramental	Practical	Suggestions	Disability Etiquette	Definitions	People 1st	Language	Inspirations	Resources/Links	Attitudes &	Causes	Social Justice	That the Website	is there!

## APPENDIX P

# SURVEY SENT TO PARTICIPANTS WHO DID NOT RESPOND TO THE POST-SURVEY AND THE RESULTS

P.1: EMAIL SURVEY SENT TO PARTICIPANTS
WHO DID NOT RESPOND TO THE POST-SURVEY
P.2: RESULTS OF SURVEY SENT TO PARTICIPANTS WHO
DID NOT RESPOND TO THE POST-SURVEY

## P.1: Email Survey Sent to Participants Who Did Not Respond to the Post-Survey

Sent February 6, 2007

Hello,

I'm writing you because I am nearing the end of my Doctorate program. In October, I sent you a Post-Survey asking you to critique the website www.catholicdisabilityteachings.com

The advisors for my project have asked me to follow with those who did not respond to the postsurvey. I have two short questions which will take less than a minute.

If you would, please hit return and fill in the following questions. Please return this survey by this Friday, February 9<sup>th</sup>.

Thank you for your assistance in this project! Please feel free to continue visiting the website and contact me if I can be of any assistance.

God Bless Dennis	You!
Name:	Email Address:
Question #	1: Please complete the following by selecting one response.
I d	lid not return the Post-Survey because:
_	I forgot to complete it
	Other items in my life (work, home life) became more pressing
	I lost interest in the project
respond	I did not visit the website as often as I had expected and did not feel qualified to
	I didn't receive it
	Other Reason (Please use as much space as you wish):
	#2: Would you like to be notified periodically when the website is updated? (Check)
That's it!!	
I appreciat	e your response
Dennis	

# P.2: Results of Survey Sent To Participants Who Did Not Respond To the Post-Survey

## Follow-Up Survey

After tabulating the post-survey, the author conducted a follow-up survey to determine why 127 people had not responded. To accomplish this quickly, he created a survey (see appendix P.1) that was sent to 61 people. The author chose individuals who had email addresses and had completed the pre-survey. Responses are found in the table below. No negative responses were indicated.

Surv	eys Sent	Surveys Received	Percentage
	61	34	56%

Reasons for not returning the Post-Survey:	Total	% of 34
I forgot to complete it.	2	6%
Other items in my life (work, home life) became more pressing.	9	26%
I lost interest in the project.	0	0%
I did not visit the website as often as I had expected and did not feel qualified to respond.	6	18%
I didn't receive it.	1	3%
Other Reasons  In the hospital Lost in the mess at my office and never mailed. Primary email address changed and I had not been keeping up on the projects progress. Elderly father was ill and taking care of him was priority. Technical difficulties with the computer. In the hospital. Technical difficulties with the computer.	7	21%
Emails were returned because the mailbox was full or the addresses were no longer in use	12	35%

## APPENDIX Q

## DIOCESAN MODELS OF MINISTRY TO PERSONS WITH DISABILITIES

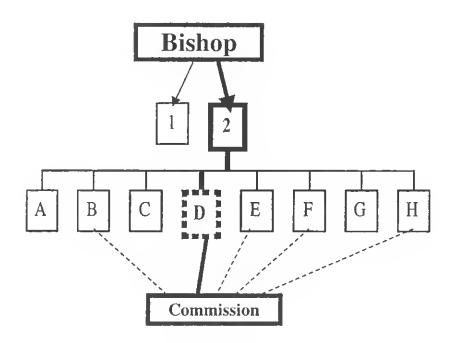
## Diocesan Models of Ministry to Persons with Disabilities

There is no one way in which to structure ministry with people with disabilities in a diocese. Various factors within a diocese determine the ways in which this ministry is established and carried out.

The models on the following pages are offered as examples of current successful structures within various dioceses in which people with disabilities are being called to full membership in their faith communities. These models and descriptions are taken from *Opening Doors to Persons with Disabilities*. <sup>178</sup>

#### MODEL 1:

Commission composed of directors of various offices with the director of Office D coordinating activities and facilitating meetings.



The Commission acts as a consulting body in instituting ministry with persons with disabilities and in implementation of all diocesan guidelines and/or policies from a disabilities perspective. Following the bishop's approval of policies recommended by the commission, implementation becomes the responsibility of the diocesan office under which the policy would normally fall: e.g., Catholic Education, Family Life, Building

<sup>&</sup>lt;sup>178</sup> Janice L. Benton and Mary Jane Owen. Organizational Models of a Universally Designed Ministry, *Opening Doors to Persons with Disabilities* vol. II: The Resource File (Washington, DC: National Catholic Office for Persons with Disabilities, 1995), Ch. 2.A, 18-24.

Commission, Vocations, Worship, Adult Spiritual Formation or Pro-Life. The coalition further assists the bishop by recommending goals for ministry at the diocesan level, planning activities, and supporting awareness through media and education.

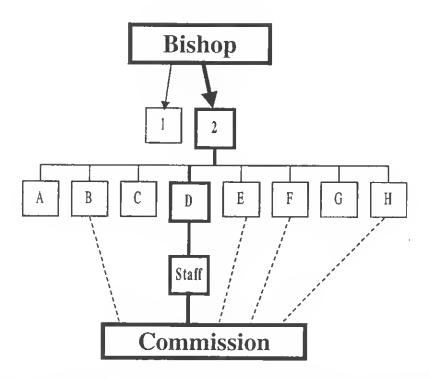
While these myriad goals, objectives, and tasks may seem prohibitive for one person to accomplish, they should be seen as a process to be achieved over time and with the assistance of staff, volunteers, and colleagues. Additional goals and objectives will be added to address issues identified through the above process.

Office space is provided at the diocesan center, located with other diocesan offices. A modest budget is established to handle expenses. Office supplies and a telephone are incorporated into the budgets of the offices making up the ministry.

The office designated by the bishop as the primary collaborating office serves as the contact for anyone requesting assistance from the diocese regarding disability concerns. The director of the office refers the request to the most appropriate person to handle the situation. For example, if a parish decides to install an elevator in the church, the request would be referred to the Office of Sacred Worship, which handles all church renovations. A request for assistance for a child with developmental disabilities to prepare for and receive a sacrament would be handled by the Office for Catechetics in conjunction with the Office of Family Life. This essential collaboration among diocesan offices is sustained through the commitment of each director to the importance of disability concerns as an integral part of each ministry.

### **MODEL 2:**

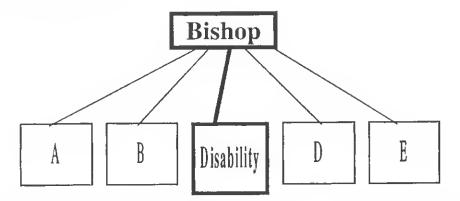
Commission composed of directors of various offices with staff/consultant assigned to Office D's coordinating efforts.



A commission is established as in Model 1, with the addition of a paid consultant staff person. The consultant has specific background in disability concerns and religion. The consultant attends commission meetings for continuous education on the ministry, review of on-going business, planning programs, and responding to needs that arise. The consultant also provides resources to the ministry, attends national and local gatherings on disability, and provides education to a variety of groups requesting assistance on disability concerns.

### MODEL 3:

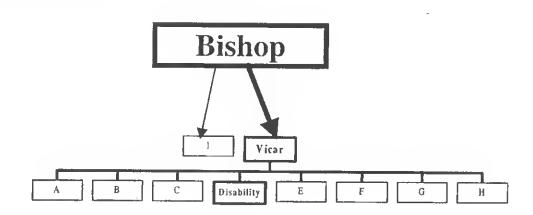
Separate office for ministry related to disability, which is directly answerable to the bishop or his designee.



Disability ministry is conducted by one or more staff persons whose sole responsibility is to address disability concerns within the diocese. Ideally, director acts as a consultant, infusing disability perspectives and action at all levels. and within all the departments and offices of the diocese.

#### MODEL 4:

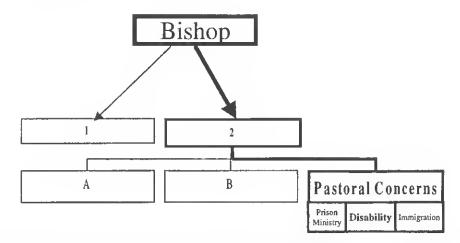
Separate office for ministry related to disability, which is answerable to the bishop through the vicar.



Disability ministry is conducted by one or more staff persons whose sole responsibility is to address disability concerns within the diocesc. Ideally, director acts as a consultant, infusing disability perspectives and action at all levels, and within all the departments and offices of the diocese.

### MODEL 5:

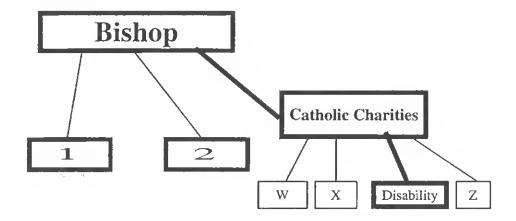
Appropriate office assigned responsibility for disability ministry as a part of a diverse staff assignment load.



In many dioceses, it has been determined that disability is one assignment among many compatible ministries. In this case, the director may be responsible for pro-life activitics, faith formation, AIDS ministry, and social concerns. The challenge in such a position is to schedule adequate time to cover these diverse responsibilities. The approach described throughout this section, of the director as an enabler rather than provider of direct service, as well as a consultant and collaborator, offers a method by which this model can adequately address the concerns of Catholics with disabilities.

#### MODEL 6:

Separate office for ministry related to disability, which is answerable to the bishop but housed outside the structure.



Responsibilities same as 3 above. Because the ministry is housed outside the (chancery structure (e.g., Catholic Charities, separate religious entity), director needs to ensure that he or she will have access to and authorization to contact diocesan personnel at all levels.

# ANNOTATED BIBLIOGRAPHY SELECTED SOURCES

### Pastoral Resources

Benton, L. Janice, and Mary Jane Owen. *Opening Doors to Persons with Disabilities* vol. l: Pastoral Manual. Washington, DC: National Catholic Office for Persons with Disabilities, 1995.

\_\_\_\_\_. *Opening Doors to Persons with Disabilities* vol. II: The Resource File. Washington, DC: National Catholic Office for Persons with Disabilities, 1995.

This two volume work is the closest thing to an encyclopedia on disability facts and pastoral considerations. Volume one begins with the Church's call to inclusion. It presents useful models for diocesan disability ministries, as well as parish programs to welcome people with disabilities. Volume two presents pastoral issues with in ministry and moves from the church to our role as advocates in society. This work comes in binders to easily remove or add sections. It may be 10 years old but it is still a must for any disability reference library.

Bernardin, Joseph Cardinal, and Rev. Henri Nouwen. *Open Hearts, Minds and Doors: Embodying the Inclusive and Vulnerable Love of God.* Chicago: Pathways Awareness Foundation, 1999, Video.

Joseph Cardinal Bernardin of Chicago and Henri Nouwen explain ways that inclusion is possible and desirable in the church community. The video highlights the importance of including persons with mental, physical, and emotional differences into Liturgy and church life. The theme is to encourage all to bring their gifts to God's altar. This can be used as an introduction to a parish committee interested in welcoming people with disabilities into the parish community.

Bishop, Marilyn. *Disability Etiquette*. Dayton, OH: Institute for Pastoral Initiatives, University of Dayton, ND. Video.

A presentation by Marilyn Bishop on the topic of proper etiquette when with a person with a disability. It presents suggestions on how to act when first meeting a person with a disability. The content is useful, but the format is dated and would not capture a group's attention.

Harding, G. T. We Grow in Faith Together: The Catechist Manual of the Rose Fitzgerald Kennedy Program to Improve Catholic Religious Education for Children and Adults with Mental Retardation. Pittsburgh, PA: The Diocese of Pittsburgh, 1996.

This curriculum is intended for persons with cognitive disabilities, ages 5 to 18. It can be adapted for people with other disabilities and for typical people as well. It is divided into levels which present themes of catechesis. It is easy to follow and very logical. The only negative point is that the teaching techniques seems to rely too much on verbal expression (words) and does not employ enough symbols, pictures, and other non intellectual means to share faith. In the end, every curriculum must be adapted to the needs of the individual.

Huber, Nancy. *A Deaf Child's Spiritual Journey*. Chicago: Office for the Deaf, Archdiocese of Chicago, 1982, Video.

The video was made in 1982 in Cleveland, Ohio by the Office for the Deaf, Archdiocese of Chicago at a workshop sponsored by National Catholic Office of the Deaf. The four boys were from Holy Trinity Day Classes for the Deaf in Chicago, Ill. The video is a thought provoking interview of four deaf children and their experience of religion development. How do concepts such as "God," form in a Deaf world?

Macken, Rev. Patrick. *The Inclusive Catholic Community*. Dayton, OH: Institute for Pastoral Initiatives, University of Dayton, ND, Video.

This light theological video invites the observer to consider the Church as an *inclusive* Church called to serve all. It is practical and could be used for parish discussion groups, a social action committee or any community considering the place of persons with disabilities in their community.

United States Conference of Catholic Bishops, *Catechism of the Catholic Church*. Washington: USCCB Publishing, 1995.

This Catechism conveys the Catholic Church's essential teachings clearly, concisely, and in a way that speaks directly to practicing Catholics. Because of its interfaith openness, it relates to readers far beyond the borders of Catholicism.

#### Pastoral Statements

Bernardin, Joseph Cardinal. Access to the Sacraments of Initiation and Reconciliation for Developmentally Disabled Persons. Chicago: Liturgy Training Publications, 1985.

This work was accepted as the statement of access for the Catholic Diocese of Cleveland in 1987. Joseph Cardinal Bernardin's pastoral statement for the Archdiocese of Chicago is a beautiful work on the theological rationale for the access to the Sacraments of Initiation and Reconciliation for people with cognitive disabilities. It gives pastoral suggestions and reflections. It is based strongly on "Relationship Theology."

Catholic Bishops' Conference of England and Wales. *All People Together*. Catholic Bishops' Conference of England and Wales, London, 1981.

An early pastoral statement, *All People Together* gives practical advice on integrating persons with disabilities into Church life. This one is singled out because it is referred to in numerous books and essays as a model of a pastoral statement for a Diocese. In addition, this has been the basis for many pastoral statements that exist today.

John Paul II. *The International Year of Disabled Persons*. Washington, DC: National Catholic Office for Persons with Disabilities, 1981.

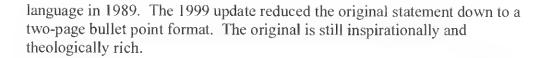
Since the 1970's the Vatican has released many statements on the place of persons with disabilities in the Church. This statement is selected because it offers a brief theological basis for the integration of persons with disabilities.

United States Conference of Catholic Bishops. *Guidelines for Celebration of the Sacraments with Persons with Disabilities*. Washington, DC: National Catholic Office for Persons with Disabilities, 1995.

These statements provide the most recent American guidelines to sacramental celebrations with persons with disabilities. Very general, they still offer a basis for an attitude of sacramental *welcoming*.

. Pastoral Statement of U.S. Catholic Bishops on People with Disabilities. Washington, DC: National Catholic Office for Persons with Disabilities, 1978 updated 1989 and 1999.

This pastoral is the landmark statement of the Bishops of the United States on persons with disabilities. It is the foundation of the Catholic inclusion movement that continues today. Because of it, the USCCB created the National Catholic Office on Disabilities to assist dioceses. This pastoral was updated in



\_\_\_\_\_\_. Principles, Prophecy, and Pastoral Response, An Overview of Modern Catholic Social Teaching. Washington, DC: National Catholic Office for Persons with Disabilities, 2001.

In this short work, the U.S. Catholic Conference of Bishops gives a thoughtful description of the social teachings of the church and how modern day Catholics might respond.

\_\_\_\_\_. Welcome and Justice for Persons with Disabilities: A Framework for Access and Inclusion. Washington, DC: USCC Publishing, 1999.

A good resource on principles that call the Church to integrate persons with disabilities, this work provides the foundation of social justice principals as the intrinsic rationale of providing access to Church for persons with disabilities.

### Books / Articles

Beal, John P., James A.Coriden, and Thomas J. Green, ed. New Commentary on the Code of Canon Law. Mahwah, NJ: Paulist Press, 2000.

Canon Law is essential to understanding the Church's approach to persons with disabilities, especially in terms of sacramental access. Beal's commentary is very easy to follow and interprets the codes in plain English. This book is a very valuable resource.

Behrmann, Rt. Rev. Msgr. Elmer. *Catholic Special Education*. St. Louis, MO: B. Herder Book Co., 1971.

As an early work in the area of special education, Behrmann presents a good theological and practical approach to educating persons with disabilities. What is very interesting is that he is not focused on one group. There are chapters that cover persons with cognitive disabilities, the Deaf, Blind, and physically challenged. Its wide scope seems to be due to the experience of the author who served for President Kennedy on the *Panel on Mental Retardation* and his experience as the director of the Special Education Department of the National Education Association. A very good historic source and perspective from 1971, before any pastoral statements or legislation for education and services for persons with disabilities existed. This is one of the only sources of historical information the author has found on the development of Catholic special education, tracing its roots back to the nineteenth century. Page thirty-four calls

for the creation of inclusive Catholic educational systems. This book is ahead of it's time and a good source for the historian.

Bishop, Marilyn E., ed. *Religion and Disability, Essays in Scripture, Theology and Ethics.* Kansas City: Sheed & Ward, 1995.

Bishop presents three addresses from the national symposium, "Ministry Perspectives on Disabilities." The first by Donald Senior identifies certain themes often associated with scripture, such as the distinction between clean and unclean, and the notion that sin and guilt sometimes cause sickness and disability, that contribute to non-welcoming attitudes toward people with disabilities. In the second, John Macquarrie reflects on the dignity of all persons applying it especially to persons with disabilities. Finally, Stanley Hauerwas imagines a church community enriched by its members who are disabled. A reflective work this piece assists in providing foundational ideals as to why one should integrate persons with disabilities into the life of the church.

Blair, William A. "Who will move the Next Mountain? Congregational Hospitality and Community Involvement," Journal of Religion in Disability and Rehabilitation, 2 (4): 1996, 81-90.

Blair considers traditional attitudes of religious communities regarding persons with disabilities. He discusses religions' unique potential in advocating for quality of life and dignity. Blair offers suggestions on how communities can be more welcoming and integrate persons with disabilities into their community.

Browne, E. J. *The Disabled Disciple: Ministering in a Church without Barriers.* Liguori, MO: Liguori Publications, 1997.

Using statements from Vatican II Browne presents a servant model of ministry to persons with disabilities based on an ecclesiology of a community of acceptance on its way to the *Kingdom of God*. Browne who happens to be blind writes from a personal perspective of the experience of exclusion. She presents a work that is very hope-filled speaking of the progress that has been made which letting the scripture, pastoral statements, and her reflections challenge us as Church to further growth. This book is very easy to read and would make a good study guide for any parish group considering the call to welcome people with disabilities in to full participation in the Church.

Canon Law Society of America, ed. *Code of Canon Law*. Washington, DC: Canon Law Society of America, 1998.

This source, along with the on-line version cited below, were the sources employed in this project. Canon Law is essential to understanding the Church's approach to persons with disabilities, especially in terms of sacramental access.

Clarke, B. *Enough Room for Joy, Jean Vanier's L'Arche*. Toronto: McClelland and Stewart Limited, 1974.

Clarke presents a personal reflection and introduction to the L'Arche Community created by Jean Vanier. It presents a good background to understanding the purpose and mission of the movement and the religious motivation of Vanier. This serves as an introduction to the other works presented here by Vanier.

Congar, T., "The Notion of 'Major' or 'Principal' Sacraments." *The Sacraments in General*, ed: E. Schillebeeckx and B. Willems, Concilium 31, pp. 21-32. New York: Paulist, 1968.

A sort essay, Congar presents arguments that there are "major" and "minor" sacraments. The basic concept is that, in view of their content, and their place in the saving structure of the Church, there are major sacraments that are essential in a member's life. This work is good for its historic references.

Davis, Lennard J. The Disability Studies Reader. New York: Routledge, 1997.

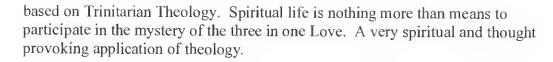
Davis, by assembling classic and challenging essays as well as fiction and poetry from the field of disability studies, has compiled an interesting work. This work is valuable for its breath of divergent approaches to the issues of disability. Most notable are the historical chapters dealing with periods not often treated. Using divergent sources and approaches Davis points out how disability studies fit into the established critiques of race, class, gender and sexual orientation.

Deland, Jane S. "Images of God Through the Lens of Disability," *Journal of Religion, Disability and Health*, 3 (2): 1999, 47-81.

Deland presents a liberating theology of disability based on biblical images of God and upon the perspective of persons with disabilities. She calls for a new image of wholeness and healing to understand a different facet of God. To see the image of God in each person who is disabled, disability must be viewed through a different conceptual lens. Her point is that a disability in no way detracts from our essential being. In fact, it enhances our understanding of the person.

Downey, Michael. Altogether Gift, a Trinitarian Spirituality. New York: Orbis Books, 2000.

Based on the Trinitarian Theology of Catherine La Cugna, Downey presents a reflection on the Trinity as central to Christian life and faith. He applies theology to the way that the Trinity speaks to the deepest desire of the human heart. He presents the Trinity in accessible language to encourage a spirituality



\_\_\_\_\_. "Trinitarian Spirituality." Eglise et Theologie, 24 (1993): 109-23.

This work was very important to the theological section of this project. Downey takes La Cugna's Trinitarian Theology, critiques it and applies it to persons with severe disabilities. His point is to underscore the *personhood* of individuals with cognitive disabilities by defining God's essence as *relationship* and not cognitive abilities. "Trinity" is a practical doctrine for life in Christ through the Holy Spirit. "Trinitarian ... spirituality ... corrects ... the relationship between action and contemplation" as components of the same sphere: "the sacred and the secular..." ... "God ... in the economy of salvation is not only God for us but for the whole world." (p.122)

and Catherine Mowry LaCugna. "Trinitarian Spirituality," *The New Dictionary of Catholic Spirituality*, Minnesota: Liturgical Press, 1993, 968-982.

As with the previous two works cited, this writing presents a good overview of Trinitarian Spirituality and how this belief impacts all aspects of the Christian's life especially in terms of one's spirituality.

Dulles, Avery. "Imaging the Church for the 1980," A Church to Believe In; Discipleship and the Dynamics of Freedom. New York: Crossroad Publishing Co., 1982.

Dulles pulls together ten essays published since 1977 that attempt to refine and enhance the ideas proposed in the original version of *Models of the Church* published in 1974. He deals with the issue of the credibility of the Church in the post-modern world. Of particular interest to my project is his presentation of the Church as a community of disciples. This model has applications to persons with disabilities and their role in the Church as full participants.

\_\_\_\_\_. *Models of the Church*, 2<sup>nd</sup> Edition (Expanded Edition). Dublin: Gill and MacMillan, 1988.

Avery Dulles, one of America's leading theologians, surveys the different understandings among Protestant and Catholic theologians of what a church is and sums them up in Models of the Church. Six major models emerge: the church as institution, mystical communion, sacrament, herald, servant, and community of disciples. The models can be applied to persons with disabilities as an ecclesiological foundation which necessitates the integration of persons with disabilities in all aspects of Church life.

Eiesland, Nancy L. *The Disabled God: Toward a Liberation Theology of Disability*. Nashville: Abingdon Press, 1994.

The author, who has a disability, argues that the "hidden history" of non-conventional bodies living ordinary lives with grace and dignity, disgust and disillusion, can make both a theological and pastoral contribution. She affirms that bodies in trouble, that lumber and plod their way through life, are in full continuity with humans' ordinary lives, filled with blessings and curses.

\_\_\_\_\_. "Encountering the Disabled God," The Other Side, 38 (5): 2002, 10-15.

Eiesland discusses how the church often alienates persons with disabilities with distorted theology. She treats, specifically, the hindrances persons who are physically or mentally challenged encounter when being barred from ordained ministry. She considers disability as linked to sin and the acquiescence to social barriers as a sign of obedience. This is an interesting consideration from a liberation viewpoint.

\_\_\_\_\_ and Don E. Saliers. *Human Disability and the Service of God: Reassessing Religious Practice*. Nashville: Abingdon Press, 1998.

Eisland and Saliers have compiled and edited diverse essays covering areas of theology from interpretation of scripture to applications of the current disability movement to church life to practical applications for the pastoral minister. This ecumenical approach is one of the most diverse treatments of disability issues and theology that I have encountered. A valuable resource for the student for those preparing for, or those currently serving in ministerial roles.

Foley, Edward. *Developmental Disabilities and Sacramental Access*. Collegeville: The Liturgical Press, 1994.

Is a developmental disability an appropriate reason to bar baptized persons from receiving the sacraments? This is the question that created this book. An excellent short volume, this work covers many aspects of sacramental access. It is a mixture of stories and good concise theology. There are many chapters that are valuable but Huels' *Canonical Rights to the Sacraments* (chapter 5) and Francis' *Celebrating the Sacraments with those with Developmental Disabilities* are outstanding for their concise treatment of their subject matter. This work would be an excellent text for a graduate level program on disability Sacramental Theology.

Gaventa, William C., MDiv. and David L. Coulter, MD. Spirituality and Intellectual Disability: International Perspectives on the Effects of Culture and Religion on Healing Body, Mind and Soul. New York: The Hawthorn Pastoral Press, 2001.

A clinical work, the title says it all. Gaventa and Coulter present "International Perspectives on the Effects of Culture and Religion on Healing Body, Mind and Soul" of persons with disabilities. This is not an easy read and would not be useful for practical pastoral purposes. Its purpose is simply to provide an insight into the effect that spirituality adds to the lives of people with cognitive disabilities.

\_\_\_\_\_. *The Theological Voice of Wolf Wolfensberger*. New York: The Hawthorn Pastoral Press, 2001.

Wolf Wolfensberger is typically not well known in theological circles. He expounded positions in the 1970's and early 80's on topics such as integration, deinstitutionalization, and program evaluation. But he had many things to say in the area of religion. Dr. Wolfensberger runs the gamut from clinical, psychological issues in mental retardation to the role of life, death, and spirituality in all of our lives, including those with disabilities. This volume brings together his theological papers and presents his thoughts on the place of spirituality and the role of the church in encouraging participation. It is an interesting spiritual perspective from a clinical psychologist. The section on a "Theology of Social Integration of Devalued/Handicapped People" is particularly interesting in that the theology is based on social justice principles as well as the biblical call for integration.

Goleman, Daniel. Working with Emotional Intelligence. New York: Bantam Books, 1998.

Emotional Intelligence is a theory that the technical skills and amount of intelligence that an individual possesses has little to do with job success. Rather, this theory focuses on personal qualities, such as initiative and empathy, adaptability and persuasiveness as the foundation of a successful work-life. Goleman is dealing with the work place. But using the work place as metaphor these principles and outlook can be applies to the church and its various ministerial roles. In this context person with disabilities can be accepted on a more equal footing to participation in the life of the church. Putting intelligence second to personal qualities people with disabilities can be encouraged to participate fully in church life. Pastorally this book has applications as to how we provide catechesis. Catechesis should involve the growth of the entire person in a relationship with God and not just the passing on of intellectual information. The ramifications can impact our theology of sacramental reception to ministerial roles of leadership in the church.

Haight, Roger. "The Point of Trinitarian Theology." *Toronto Journal of Theology* 4 (1988): 191-203.

Haight presents his interpretation of Trinitarian Theology. As with the other sources on this subject, the point is to approach the Trinity as a practical dogma that speaks on the action of God in people lives. ... "The point of "'Trinity' is that God is ... one, that God's saving action in Jesus and the Spirit are real, and that therefore God as such is a saving God." "... The qualities of God revealed in Jesus and experienced ... as God's Spirit are elements of the very reality of God." (p. 202)

Hall, S.E., ed. *Into the Christian Community*. Washington, DC: National Catholic Educational Association, 1982.

Hall presents a short consideration of religious education with persons with cognitive disabilities. It presents an early voice calling for inclusive approach to catechesis. To Hall, "Christian community, by its very definition, implies inclusion, caring, support, and non-segregation... We as a Church cannot continue either to ignore or to segregate disabled people." Historically, its value is to show the leadership voices of the Church calling for approaches that society has yet to truly embrace. Although the wording is antiquated this book is valuable. To my knowledge, however, it is no longer in print.

Harrington, Mary Therese. "The Rights of Persons with Developmental Disabilities to Receive the Sacraments," *New Theology Review*, 7 (3), 1994, 65-68.

Harrington presents a brief discussion on the rights of persons with cognitive disabilities to receive the sacraments. She targets Reconciliation, Eucharist, Confirmation and Anointing of the Sick. She calls for a reexamination of the "having the use of reason" criteria in light of child development insights. Access to the sacraments is called for based on the relationships of the individual and a developing sense of the sacred.

Hauerwas, S. Suffering Presence, Theological Reflections on Medicine, the Mentally Handicapped, and the Church. Notre Dame, In: Notre Dame Press, 1986.

Considering that this was published in 1986, Hauerwas presents an interesting treatment on ethical issues that are still being debated. It pre-dates the present debates but, as such, gives a good historical perspective to current dialogue. Theological perspectives as well as ethical considerations are presented on diverse areas such as suffering, end of life issues, general medical approaches to persons with disabilities and even consideration as to the ethics of preventing mental retardation. A very interesting chapter completes the work by considering "Community and Diversity: The Tyranny of Normality (pp. 211ff). This chapter challenges the, then, new concept of "normality." This is one of the earliest works to do so.

Hogan, G., ed. *The Church and Disabled Persons*. Springfield, IL: Templegate Publishers, 1983.

Griff Hogan, Director of the *Apostolate for the Mentally Retarded*, Catholic Diocesc of Cleveland, Ohio, edits a compilation of essays that present the Church' approaches to persons with disabilities in the general areas of ministry and education. Hogan presents a good, concise history of special religious education. The value is that this work examines the state of persons with disabilities in 1983 and the responsibilities of the church and its members to follow the requirements of justice and brotherhood contained in the social teachings of the Church. It contains challenges that still need to be answered.

\_\_\_\_\_\_, ed. "A Guide to Special Religious Education in the Diocese of Cleveland." Non-published: Archives, Catholic Diocese of Cleveland, OH, 1980.

Griff Hogan, Director of the *Apostolate for the Mentally Retarded*, Catholic Diocese of Cleveland, Ohio, along with his staff wrote a guide for religious education for persons with cognitive disabilities in 1980. Most notable is his philosophy of special religious education (pp. 1 ff.) and the bibliography which is quite extensive for such a short work which covers only 50 pages with bibliography and appendix. It is of interest in an historic context. It shows that, although antiquated, basic approaches to people with cognitive disabilities can be applicable even in a more *informed* society. (Truth is truth.)

Huels, John M, O.S.M. *One Table, Many Laws: Essays on Catholic Eucharistic Practice*. Collegeville: The Liturgical Press, 1986.

A very good collection of Huels' essays mainly dealing with Eucharistic practices. Most useful to the theological section of this project was chapter 4. "The Eucharist and the Mentally Handicapped." In this chapter Huels concisely takes cannon law and applies it to the question of the right of persons with severe cognitive disabilities to receive the Eucharist. Also, very useful is his explanation of the nature of Canon Law and interpreting it using Orsy's rules of canonical interpretation. Orsy states that "no law should be applied literally and exclusively, but each should be used with discretion and in conjunction with the others." (p. 19)

. "Use of Reason" and Reception of Sacraments by the Mentally Handicapped." *The Jurist* 44 (1984):1. XLIV, pp. 209-219, The Catholic University of America. Washington, DC, 1984.

As with the previous work cited by Huels, this work is simply an earlier essay of the subject of reception of the sacraments by individuals with cognitive disabilities. This essay speaks more generally on the application of Canon Law to the reception of the sacraments in general.

Irwin, Kevin W. Models of the Eucharist. New York: Paulist Press, 2005.

Irwin reflects on the celebration of the Eucharist in the Catholic Church. His purpose is to present models, similar to the *modus operandi* of Dulles, of what is happening when Mass is celebrated and the meanings it holds in terms of Catholic beliefs and living a Christian life. It is relevant because it underscores the diverse interpretations of the meaning of Eucharist. It is traditional in the sense that it draws on classic descriptions, such as *transfinalization* and *transsignification* and translates them in contemporary models that are much more accessible without sacrificing *transubstantiation*. It presents a good foundation for a diversity of models for understanding and interpreting the Eucharist. Chapter Nine, *Active Presence*, is particularly relevant to the discussion on the real presence.

Johnson, Maxwell E., ed. *Living Water, Sealing Spirit*. Collegeville: The Liturgical Press, 1995.

This ecumenical collection of essays on Christian initiation from a number of liturgical scholars presents analyses of ancient sources and challenges to the traditional interpretations of those sources, an investigation of the development and meaning of "confirmation," descriptions and interpretations of contemporary initiation rites, and a discussion of the challenges and opportunities offered by infant initiation. They are conveniently collected together here for all who seek a solid foundation in initiatory theology and history leading to an informed pastoral practice in the churches today.

Kern, Rcv. Walter. *Pastoral Ministry with Disabled People*. New York: Alba House, 1985.

Kern presents a good overview of the rationales for sacramental access for persons with disabilities. The chapter on reception of the Eucharist is very good in its treatment of historical traditions and theologies through the ages that treat the question of who should receive and under what conditions? The chapter "Why me/us, Lord?" gives good pastoral advice to understanding disability as a family issue. This one chapter makes this book worthwhile for pastoral suggestions. The wording is archaic but can be forgiven considering the year in which it was written.

La Cugna, Catherine Mowry. *God for Us, the Trinity and Christian Life*. San Francisco: Harper San Francisco, 1991.

La Cugna states, "...the doctrine of the Trinity, properly understood, is the affirmation of God's intimate communion with us through Jesus Christ in the Holy Spirit. As such, it is an eminently practical doctrine with far-reaching consequences for Christian life." Presenting the doctrine in such a way, La

Cugna connects Trinity with other areas of theology, including the *personhood* of all human beings.

An excellent synopsis of her book, *God for Us: The Trinity and Christian Life.* "Trinity" is a summary of our faith in God, which "points to the shared life of God and God's creation in the economy of providence..." It "... remind(s) us to 'taste and see the goodness of God' revealed in creation, Christ and communion with one another in the Spirit." (p. 682 applications of this to the complete *personhood* of persons with disabilities are extensive and the ramifications challenge our conventional attitudes of the *incompleteness* of members in our society who lack cognitive or physical abilities.

Longmore, Paul K. and Lauri Umansky, editors. *The New Disability History*. New York: University Press, 2001.

Longmore and Umansky present a series of essays to fill an historical gap. The essays demonstrate how disability has had a place in many aspects of our history and in the various social movements of our society. The essays point out the commonality of *disability* almost every historical situation. This is the book's strength; that it points out that people with disabilities have played a part in the creation of our present society. An interesting approach, this work is similar to works that present the influence of other groups in the development of present day America, such as research in the history of African Americans. Historically important to current attitudes toward people with disabilities is the section that treats the philosophy of eugenics as it impacted various groups of people with disabilities. The authors clearly makes the case that disability is everywhere in history as in society.

Meyer, John. "The Religious Education of Persons with Mental Retardation." *Religious Education*, 81(1), 1986, 134-139.

Meyer reflects on Public Law 94-142 and how in this time of societal change toward people with cognitive disabilities in which *normalization* is the trend, that the church has implemented little, if any, of these principles in their approach to religious education. In contrast, the church continues to segregate persons with disabilities. In his view, the church views the person with cognitive disabilities as either super-human or sub-human. Too often the approach is one of pity. He applies very common sense approaches to encourage the church to respond to the person simply as genuine human beings.

Muller-Fahrenholz, G., ed. *Partners in Life: The Handicapped and the Church*. Geneva: World Council of Churches, 1981.

Muller-Fahrenholz brings together diverse collaborators, such as people with disabilities, parents or relatives of persons with disabilities, social workers, pastors and theologians, to present an international, ecumenical work dealing with theological issues in the lives of people with disabilities. Written in 1981, in the spirit of the United Nations' *International Year of Disabled People*, the churches of the world use this opportunity to renew their commitment to be *partners in life* to the glory of God. This book underscores the universality of the call to inclusion of all people.

Nouwen, H.J.M. *The Road to Daybreak, A Spiritual Journey*. New York: Doubleday, 1988.

Henri Nouwen's intimate, inspiring diary of his first year in the L'Arche community called Daybreak, where he now made his home and practiced his ministry. Here he uses the intimate journal format to share his journey from the intellectual milieu of the Harvard Divinity School to his new call to be priest at Daybreak, Toronto's L'Arche home. "How does one follow Jesus unreservedly?" Struggling to answer this question, Nouwen shares his own vulnerability in transparently honest ways that will both nurture and challenge readers to move "closer to the heart of God" in their own lives. A wonderful book for the minister trying to understand their role in ministering to persons with cognitive disabilities.

\_\_\_\_\_. Adam: God's Beloved. Maryknoll, New York: Orbis Books, 1998.

"Henri Nouwen completed *Adam: God's Beloved* just weeks before his death in 1996. It is a personal memoir about his friendship with Adam, a severcly handicapped man he knew at the L'Arche Daybreak Community in Canada. Although Adam could not speak and was wracked with violent seizures, Nouwen called Adam "my friend, my teacher, and my guide," and credited Adam with renewing his faith in a particularly dark period of life. Thanks to Adam, Nouwen came to understand the central questions of Christian theology in a way that transcended all statements of belief, and instead found joy in the mere gift of human existence." --Michael Joseph Gross

O'Brien, John. Whose Table for 'The Retarded'?' Journal of Religion, Disability & Health, 8 (3-4). 2004, 45-52.

O'Brien applies Wolf Wolfensberger's principle of *normalization* specifically to the life people with disabilities experience within the church. He treats the role of those treated as outsiders in building community. He accents the importance of persons with cognitive disabilities as possessing affirming gifts. He presents an understanding of community building and the positive impact of applying the

principle of *normalization* in contrast to the negative effects of segregation and control.

Power, David N. *The Eucharistic Mystery, Revitalizing the Tradition*. New York: Crossroad Publishing Co., 1995.

Power's aim is to renew the celebration of the Eucharist by bringing it into closer contact with contemporary culture. Examining three key periods in the development of the tradition—the New Testament era, the time just before the Council of Nicaea, and the age of Thomas Aquinas—Power shows how the celebration of the Eucharist has always responded to the cultural milieu. His writing is accessible to the lay reader and the ecumenically sensitive.

\_\_\_\_\_. Sacrament, The Language of God's Giving. New York: Crossroad Publishing Co., 1999.

"This book intends to present an approach to sacramental worship for an interpreting Church, one that allows its members to have insight into what is going on and into how they relate to past traditions, within a present that is already passing into the future (p. 2)." This book is good, especially, for its interwoven ecclesiology as a basis for sacramental worship. The approach puts the emphasis on God's action vs. human understanding of the evolving community.

Powers, Joseph. Eucharistic Theology. New York: Herder and Herder, 1967.

Powers presents a short treatment of historical theology, biblical faith in the Eucharist and a section on the theology of the Eucharist itself. The most valuable chapter is his treatment of the real presence and *Transsignification*. The ramifications of this chapter (chapter 4) for persons with disabilities make this a valuable resource.

Russell, Letty M. *Church in the Round, Feminist Interpretation of the Church.* Louisville, Kentucky: John Knox Press, 1993.

Russell presents an ecclesiology based on the analogy of a round table. She presents an interesting interpretation of church in which there is shared authority among the community. This is pertinent as a model for people with disabilities because the model presents an awareness of and a call to include those one the margins of the church and society. This written as a feminist interpretation but is easily applicable to others such as persons with disabilities.

Schillebeeckx, Edward, O.P. *Christ the Sacrament of the Encounter with God.* New York: Sheed and Ward, 1963.

Schillebeeckx's thesis is simple: Jesus Christ is the God-Man, and salvation is only possible through a personal encounter with Christ. Christ, however, has risen and ascended into heaven. The question remains: how are people saved who have not had this personal encounter? The sacraments -- which are an extension of the primordial sacrament, Christ himself -- are established by Christ in the Church so that people of all ages may have an encounter with Christ and be saved.

\_\_\_\_\_. Church: The Human Story of God, New York: Crossroad, 1990.

Schillebeeckx presents the church as the "sacrament" of salvation and liberation for humanity. In this work he reflects and expounds on the models of the church presented by Vatican II and later theologians. His insistence on a democratic rule of the church as a community of God presents ecclesiastical insights and carries strong implications for church members including people with disabilities and their place in the church community.

\_\_\_\_\_. The Church with a Human Face, A New and Expanded Theology of Ministry. New York: Crossroads, 1985.

Schillebeeckx presents an update of his earlier work, Ministry. His purpose is to present ministry as the church moves into the second millennium. The majority of the work is an historical overview of how ministry has been defined and the models it undertook throughout history. The most pertinent section is toward the end where he considers the "complaints of the people," the current situation and the consideration of a more diverse ministerial group to respond to current needs. What he presents is new model of ministry, i.e. church in which authority and the call to serve takes on a human face because it is shared by diverse members of the community.

\_\_\_\_. The Eucharist. N. D. Smith, trans. New York: Sheed and Ward, 1968.

Schillebeeckx presents an approach to Eucharistic theology that reflects the theology of Vatican II. His treatment of *transfinalisation* and *transsignification* as approaches to Eucharistic real presence are insightful and present considerations that create paradigms that redefine how the action of Eucharist is considered. This work underscores the Eucharist as God's action and not contingent on humans' perception and understanding of the mode of real presence.

\_\_\_\_\_. "Transubstantiation, Transfinalization, Transignification," *Living Bread, Saving Cup*, R. Kevin Seasoltz, O.S.B., ed. Collegeville: The Liturgical Press, 1987. 175-189.

This work is a collection of essays of various authors on Eucharistic Theology. Schillebeeckx uses Vatican II theology to re-evaluate Eucharistic theology with an appreciation of several "real presences" of Christ in the Eucharistic. Considering three approaches to the real presence, he emphasizes the action of Christ in the Eucharist, an action that may not always necessitate a cognitive understanding of transubstantiation for reception. Presenting various approaches to real presence has great application to persons with cognitive disabilities.

Senge, Peter M. The Fifth Discipline. New York: Currency Doubleday, 1990.

Senge presents a work geared toward major corporations that wish to last and flourish. His premise is that the only sustainable source of competitive advantage is an organization's ability to learn faster than its competitors. So what is this book doing in a project for a doctorate in ministry? Simply put, if read with application to the church and its call to announce the Kingdom at hand and yet to come, these principles can be applied to the functioning of the church. Going forward the church must be a *learner* of new ways to answer Christ's call. New ways to minister, to evangelize, to call forward and to include must be found and must remain fresh to face a post-modern society. Who is the competition? The world and its call to divide and de-humanize. A suggested read for pastoral ministers and persons of authority.

Shannon, Tresco, "Ministry and Persons with Developmental Disabilities, *Worship*, 66 (1): 1992, 10-24.

Shannon discusses the theology and ethics of ministry with persons with developmental disabilities using the liturgy of the church as an ethical statement of Christian faith and life. Her point is that the communal nature of the Christian life shapes ministry to persons with disabilities.

Sloan, W., and H. A. Stevens. A Century of Concern: A History of American Association on Mental Deficiency 1876-1976. Washington, DC: American Association on Mental Deficiency, Inc, 1976.

Essential for the historian. this book is a summary and/or meeting notes of the American Association on Mental Deficiency, presently named the American Association on Mental Retardation. This organization is the oldest American organization that promoted the lives of persons with cognitive disabilities through research, and professional publications. What this book presents is the evolution of this organization that, at its meetings, reflected the *conventional wisdom* of the times. What is revealed are the attitudes from institutionalization

to eugenic to the dawning of deinstitutionalization? As embarrassing as some of these periods appear to us in 2005, the work shows an evolution and a willingness to grow and develop. It is an important historical document.

Taylor, Steven J. "Christmas in Purgatory: A Retrospective Look," *Mental Retardation*, 44, 2:145-149, April, 2006.

Taylor looks back 40 years to the exposé in Look Magazine entitled, *Christmas in Purgatory* that assisted the close of Pennhurst State Institution and the ushering in of the deinstitutionalization movement. He reviews the work in context of major events that have occurred since in the field of cognitive disabilities. In this short article Taylor reviews some theories of normalization by Blatt and Wolfensberger. This is an easy to read overview of the philosophy of the disability movement since 1966.

Theodore, M. T., O.S.F. *The Challenge of the Retarded Child.* Jefferson, Wisconsin: Bruce Publishing, 1969.

This book was found in the archives of the *Apostolate for the Mentally Retarded (now; Catholic Charities Disability Services)*, Catholic Diocese of Cleveland, Ohio. No longer in print this work presents two interesting chapters on the history of persons with cognitive disabilities. Chapter 3 presents a history of the inhuman treatment of persons with cognitive disabilities in the United States. Many of the quotes and comments are very revealing of attitudes and are not found in any other work I have utilized. Chapter 16 presents a wider sweep of history going back to fifteen hundred years before Christ in Thebes. This chapter is very interesting for its historical perspective presented in fifteen pages. Very valuable to the historian is an extensive annotated bibliography. Sadly, no footnotes were utilized so the bibliography provides the only source of references.

Vanier, Jean. Becoming Human. New York: Paulist Press, 1999.

This book is comprised of five talks Vanier presented on the Canadian Broadcasting System (CBC) radio program *Ideas* and the 1998 Massey Lectures at Massey College of the University of Toronto. Written in very easy to follow prose Vanier follows the human heart's journey from chaos to life. Here, he presents a philosophy of human growth being the move toward a freedom that involves opening one's heart to others and discovering our common humanity. This book is applicable to anyone at almost any age in life.

\_\_\_\_\_. The Broken Body: Journey to Wholeness. Nashville: Abingdon Press, 1999.

Vanier urges the reader to walk with the poor and vulnerable so that we and they may become whole and healed. Meditational aid for internalizing practical theology.

. Community and Growth: Our Pilgrimage Together. Translated by Ann Shearer. New York: Paulist Press, 1998. Vanier presents a Bible for living in community. It is about love, healing, service, family, and community. It addresses the problem of increasing alienation, isolation and loneliness in our modern technological world. These problems and the difficulty of forming community are especially true for persons with disabilities. . Community and Growth. New York: Paulist Press, 1989. In many of his books Jean Vanier often concentrates on the individual and their growth. Here he presents community as a basis for growth. Many of the themes are similar to his other works but here they are applied to the us rather than the me.. His chapter on authority (chapter 6) is particularly good and can be a good self-examination for ministerial leaders as to the proper use and the role of authority as a gift that builds up the community. . From Brokenness to Community. New York: Paulist Press, 1994. "Vanier's "lectures", built as they are around stories from a life lived among the poor and disabled, have moved his listeners for years. Some say it is his gentleness and joy; others speak of his disarming radicalism. All note the spirit of hope. Neutral Christians beware!" (From the publisher) This is a short, inspirational book that reinforces the reason we exist which is, to love each other. Vanier presents the foundation of why we include everyone. . Jesus, the Gift of Love. New York: Crossroad Publishing Co., 1996. Jean Vanier presents a retelling of the life of Jesus in a poetic, meditational, and reflective way. Vanier is simple in his wording and style but, at the same time,

reflective way. Vanier is simple in his wording and style but, at the same time, thought provoking. This is not per se a book about disabilities. This work shows Vanier's deep faith and love of Jesus and presents the foundation of why we are called to show special love for those not considered the same as us. Jesus is the "gift of love" and we are his messengers who allow him to heal, welcome and save because we are willing to open the door.

Vatican Council II. Vatican Council II, The Basic Sixteen Documents. Austin Flannery, OP, Ed. Northpoint, New . York: Costello Publishing Co., 1995.

All references in this work to the <u>Vatican Council II</u> were taken from this edition. There are many translations but this one is preferred primarily for its inclusive language.

Vere, Peter J. J.C.L. "Calling God's Special Children to Holiness: Sacramental Access for the Mentally and Cognitively Challenged," *Proceedings of the Sixty-Sixth Annual Convention*. Canon Law Society of America, 2005.

and Ian Bergess, "The Canonical Rights of God's Special Children," *Homiletic and Pastoral Review* 103 (7): 61-62, 64-66 April, 2003.

Although written two years apart, the above works by Vere are virtually identical in content. But the content is a concise, systematic presentation of the rights of persons with cognitive disabilities to participate in the sacramental life of the church. These are very good in pointing out the pastoral obligations of the pastor when determining sacramental reception and participation for persons with disabilities.

Vogel, Jeannine, Edward Polloway and J. David Smith. "Inclusion of People with Mental Retardation and other Developmental Disabilities in Communities of Faith," *Mental Retardation*, 44, 2:100-111, April, 2006.

Vogel examines efforts to integrate persons with developmental disabilities in faith communities. She reviews literature on religious participation for persons with disabilities. She explores the impact on the quality of life, barriers to integration and strategies for overcoming these barriers. The implications for enhancing integration are presented. This is a good short update on religious efforts from a public view point.

Webb-Mitchell, Brett. Dancing with Disabilities: Opening the Church to All God's Children. Cleveland, OH: United Church Press, 1996.

Written from the theological outlook of the Presbyterian Church, Webb-Mitchell writes a personal reflection on the struggles and triumphs, frustrations and joys, of people with disabilities who he has encountered in his ministry. This work challenges the reader to image a church where the typical person and persons with disabilities or *other abilities* share a faith community as equal partners. Noteworthy is the chapter on *Liturgy* (pp. 3 ff.) which contains many suggestions for the integration of persons with cognitive disabilities into the life of the faith community. Pastorally, this presents good reflections to better understand the perspectives of people with disabilities.

. "No Longer Strangers and Aliens: Worshipping with People with Disabilities in the Church," *Worship*, 76 (4): 345-359.

Webb-Mitchell urges the church to take the next step toward moving beyond welcoming people with disabilities in certain programs such as religious education programs, to including them in the life of the church. She calls for moving beyond "inclusion" toward integrating persons with disabilities into all

that matters for Christians. There is a Trinitarian Theology at the basis of her writing. A very thought provoking piece.

\_\_\_\_\_. "A Place for Persons with Disabilities of Mind and Body," Religious *Education*, 81 (4): 1986, 522-543.

Webb-Mitchell's main point is that the presence of persons with disabilities will not diminish but will enhance the church and its mission. By experienced and educated church leaders it is her call that the church can make people with disabilities feel accepted into the community. She reviews historical perspectives on how the church has viewed people with disabilities. This is a shorter version of her longer works cited here.

\_\_\_\_\_. Unexpected Guests at God's Banquet: Welcoming People with Disabilities Into the Church. New York: Crossroad, 1994.

Written from the theological outlook of the Presbyterian Church, Webb-Mitchell presents a challenging book that present church as God's banquet-feast at which we are called to invite, welcome and include persons with various abilities. He applies this theology to many traditionally assumed programs and activities of the church. Most notable is his challenge to the educational practices of the church which, he claims, are based on logic, reasoning and cognitive skills. This paradigm, he contends, sets up a paradigm in which many are excluded from personal religious growth. His chapters on *labels* and *images of persons with disabilities* are particularly good and insightful. Of particular note is this presentation on *Perceptions of the Unexpected Guests* (pp. 11 ff).

Weiss Block, Jennie. Copious Hosting: A Theology of Access for People with Disabilities. New York: The Continuum International Publishing Group Inc, 2002.

Jennie Weiss Block views the lives of persons with disabilities through the lens of dignity. This is a refreshing treatment of a theology of access that incorporates many approaches. Most notable is her application of Gustavo Gutierrez' theology of liberation to the lives of persons with disabilities. Insightful, as well, is the presentation on Trinitarian personhood and its meaning ecclesiologically. In the end, it is the church that suffers the greatest void by overlooking the immeasurable contributions that persons with disabilities bring when they are included as full participants in the life of the church. The work, to quote Nathan D. Mitchell, is one that "...no one working in the field of pastoral care, catechesis, sacramental preparation, or liturgy can afford to miss."

Wilke, H.H. Creating the Caring Congregation. Nashville: Parthenon Press, 1981.

In this short work, Wilke speaks as an advocate for persons with disabilities and the theological basis for their inclusion in the community of believers. The result is theology of access based strongly on social justice principles rooted in the scripture. He reviews how the Church has traditionally responded or has not responded. The most reflective chapter is the one which deal with the characteristics of a caring congregation. This chapter alone is valuable as a guide for a community to determine the quality, as determined by Christian principles, of any parish decision. This work presents good guides for developing a community approach to ministry to the marginalized including persons with disabilities.

Wolfensberger, Wolf. A Brief Introduction to Social Role Valorization: A High-Order Concept for Addressing the Plight of Socially devolved People, and for the Structuring Human Services. Syracuse: Syracuse Univ., Training Institute for Human Service Planning, Leadership and Change Agentry, 1998.

Wolfensberger is a systems analyst. His theory of *normalization* and *social role valorization* became the philosophical basis for evaluating human services for persons with disabilities. The theories are very practical, intending to create an atmosphere in which services are offered in the most typical (normal) way. It is a call to treat people with disabilities as people first and to encourage their integration into typical modes of living. Even though this work pertains to human services specifically the principles can be applied to the effectiveness of a church and their approaches to the integration of persons with disabilities. There are many applications to the church.

\_\_\_\_. Passing (Program Analysis of Service Systems' Implementation of Normalization Goals), A Method of Evaluating the Quality of Human Services According to the Principles of Normalization. Downsview, Ontario: National Institute on Mental Retardation, 1983.

This work is not for the faint of heart. This is a very technical evaluation tool that evaluates the effectiveness of human service programs. But there is transferable information here. The evaluation methods could easily be translated to a church context for the purpose of evaluating the ministrics offered to people with disabilities. Wolfensberger intends to accent the *quality* of the programs. Quality is based on their ability to be offered in as typical (normal) a setting as possible to assist in the integration of people with disabilities in society and, in the context of this paper, in the church.

. "The Theological Papers of Wolf Wolfensberger." *Journal of Religion, Disability & Health*, 4 (2-3), 2001.

Wolfensberger presents a view of persons with cognitive disabilities as those who play a unique prophetic role in the church. He considers the theology of the social integration of persons with disabilities, ministry to persons with cognitive disabilities on a parish level, and the normative lack of Christian community in local congregations as the central obstacle to a proper relationship to people in need. This presents very thoughtful insights into the role of persons with disabilities in the church.

#### **Website Sources**

Websites are difficult sources of information to cite in a paper of this sort. The information can change, the site can disappear. But, there is a great deal of information on the web. Below are listed the sites that were valuable for this paper.

\_\_\_\_\_. "An American History of Mental Retardation, *The American Association on Mental Retardation* [publication on-line] (2000, accessed March 14, 2000); Available from http://member.aol.com/MRandDD/1870; Internet.

A detailed timeline is presented spanning many linked websites detailing the top historical items of each year and corresponding impact on persons with disabilities. This work is a good historical source.

. "The Disability Rights Movement: A Brief History," From Access and Opportunities: A Guide to Disability Awareness, USIA, U.S. Society and Values, USIA Electronic Journal, Vo. 4, No. 1: 1999 [publication on-line] (accessed February 14, 2006); Available from http://usinfo.statc.gov/journals/itsv/0199/jise/history.htm; Internet.

A three page synopsis of the disability rights movement, this treatment offers a concise overview of the movement since the Eugenics Movement.

. The Eugenics Movement in the U.S. [publication on-line] (Not Dead Yet, 2006, accessed April 21, 2006); Available from http://www.notdeadyet.org/eughis.html: Internet.

This anonymous short paper on eugenics cites writings since 1945 that espouse cugenic philosophies. The organization describes itself in the following words, "Since 1983, many people with disabilities have opposed the assisted suicide and euthanasia movement. Though often described as compassionate, legalized medical killing is really about a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not." This is an important perspective to consider.

\_\_\_\_\_. "Eugenics/Sterilizations," *The American Association on Mental Retardation* [journal on-line] (2000, accessed March 14, 2000); Available from http://member.aol.com/MRandDD/eugenics; Internet.

This site presents a one page overview of the eugenic philosophy but, more importantly, presents a three page time line of the American Eugenic Movement from 1859 to 1986.

\_\_\_\_\_. "Special Education," *The American Association on Mental Retardation* [journal on-line] (2000, accessed March 14, 2000); Available from http://member.aol.com/MRandDD/sped; Internet.

A very good timeline of special education in the U.S. from 1894 until 1997.

Canon Law Society of America, ed.., *Code of Canon Law* [publication on-line] ND, accessed March 29, 2006); Available from http://www.vatican.va/archive/ENG1104/\_ P36.HTM; Internet.

This on-line source in addition to the book-form mentioned above, were employed in this project. Canon Law is essential to understanding the Church's approach to persons with disabilities, especially in terms of sacramental access. This on-line resource is very easy to use for referencing sections of Canon Law.

Down, John Langdon, *A History of Mental Disability 1000 A.D.-2000 A.D.* [publication on-line] (2000, accessed March 14, 2001); Available from http://disabilities-us.com/slaterfamily/disability1.htm; Internet.

A brief bullet-point historical overview of the history of persons with cognitive disabilities offers a good comparison of movements in this disability community in context of the American society. Unfortunately, no mention is made of movements in the Church arena so this overview is simply for a social-political view.

Lydia Fecteau, *Disabled in the Modern Era*, 2/9/04 [article on-line] (2004, accessed January 30, 2006); Available from http://caxton.stockton.edu/disability/ModernEra; Internet.

Fecteau presents a short paper on the experience of persons with disabilities in the age of Eugenics. She makes references to statistics that underscore the attitude of this period as well as the current attitudes toward people with disabilities.

Koszarycz, Yuri." Models of the Church (Avery Dulles)," Ecclesiology: A Study of the Church [publication on-line] (1997, accessed April 20, 2006); Available from http://dlibrary.acu.edu.au/staffhome/yukoszarycz/ecc/CHAP3.HTML; Internet.

Yuri Koszarycz is a Senior Lecturer within the School of Theology at the Australian Catholic University, McAuley Campus, in Brisbane, Australia. His website offers an overview of ecclesiology from the Patristic era to the present. This specific section on Avery Dulles' models of the church is a concise overview of Dulles' teachings. This site chosen by The National Catholic Reporter as a most significant Catholic WEB Site, January 1997 and received the Christian Award of Excellence on January 15, 1999.

Pfeiffer, David, Ph.D. "Eugenics and Disability Discrimination, *Disability & Society*, 9 (4) [journal on-line] (1994, accessed April 21, 2006); Available from http://www.independentliving.org/docs1/pfeiffc1.html; Internet, 481-99.

Pfeiffer presents an article on-line that was in published form. He constructs a detailed writing on Eugenics and its impact on discrimination toward people with disabilities. Many references are given.